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ABSTRACT

This document is a record of a hearing on acquired immune deficiency syndrome (AIDS) and young children in South Florida. Opening statements are provided by Congressmen George Miller, William Lehman, and Richard Durbin; a fact sheet on AIDS and young children in South Florida is also presented. Testimony is presented by the following: (1) Ana Garcia, University of Miami (Miami, Florida); (2) Deanna James, C. L. Brumbeck Community Health Center (Belle Glade, Florida); (3) Manuel Laureano-Vega and Mireille Tribie, League against AIDS (Miami, Florida); (4) Reverend Roger P. Miller, Miami AIDS Interfaith Network (Miami, Florida); (5) Margaret Oxtoby, Centers for Disease Control (Atlanta, Georgia); (6) Philip Plummer, Jackson Memorial Hospital (Miami, Florida); and (7) Gwendolyn B. Scott, University of Miami School of Medicine (Miami, Florida). After the testimony, 10 sets of prepared statements, letters, and supplemental materials are appended. (TE)

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# AIDS AND YOUNG CHILDREN IN SOUTH FLORIDA

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## HEARING

BEFORE THE

## SELECT COMMITTEE ON
## CHILDREN, YOUTH, AND FAMILIES
## HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

HEARING HELD IN MIAMI, FL, AUGUST 7, 1989

Printed for the use of the
Select Committee on Children, Youth, and Families

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# CONTENTS

Hearing held in Miami, FL, on August 7, 1989 ..... 1

Statement of:

- Garcia, Ana, L.C.S.W., associate coordinator, University of Miami pediatric AIDS demonstration project, Department of Obstetrics and Gynecology, Miami, FL ..... 29
- James, Deanna, M.D., medical and executive director, C.L. Brumbeck Community Health Center, Belle Glade, FL ..... 24
- Laureano-Vega, Manuel, M.D., executive director, League Against AIDS, Miami FL, accompanied by, Mireille Tribie, M.D., assistant director, League Against AIDS, Miami, FL ..... 57
- Miller, Rev. Dr. Roger P., chaplin in AIDS ministry, and chairman of Miami AIDS Interfaith Network, Miami, FL ..... 72
- Oxtoby, Margaret, M.D., chief, Pediatric and Family Studies Section, AIDS Program, Centers for Disease Control, Atlanta, GA ..... 8
- Plummer, Philip, administrator, South Florida AIDS Network, Jackson Memorial Hospital, Miami, FL ..... 51
- Scott, Gwendolyn B., M.D., professor and acting director, Pediatric Infectious Disease and Immunology, University of Miami School of Medicine, Miami, FL ..... 17

Prepared statements, letters, supplemental materials, et cetera:

- Bliley, Hon. Thomas J., Jr., a Representative in Congress from the State of Virginia, and ranking Republican Member:
  - AIDS and Young Children In South Florida (minority fact sheet) ..... 90
  - Opening statement of ..... 87
  - "The Offensive Tactics of AIDS Ideologues," article from New York Times, August 8, 1989 ..... 98
- Bulfin, Matthew J., M.D. president, American Association of Pro Life Obstetricians and Gynecologists, letter to Select Committee on Children, Youth, and Families, dated August 18, 1989 ..... 96
- Dowdle, Walter R., Ph.D., acting director, Centers for Disease Control, Public Health Service, U.S. Department of Health and Human Services, Atlanta, GA, submitting a letter to Congressman George Miller, dated November 20, 1989, with response to questions posed by Congressman George Miller to Margaret Oxtoby, M.D ..... 105
- Garcia, Ana, L.C.S.W., associate coordinator, University of Miami, pediatric AIDS demonstration project, Department of Obstetrics and Gynecology, Miami, FL, prepared statement of ..... 32
- James, Deanna R., M.D., medical and executive director, C.L. Brumbeck Community Health Center, Belle Glade, FL:
  - Letter to Select Committee, dated November 21, 1989, with response to question, posed by Congressman George Miller ..... 111
  - Prepared statement of ..... 27
  - Laureano-Vega, Manuel, M.D., and Mirelle Tribie, M.D., executive director, League Against AIDS, Miami, FL, prepared statement of ..... 61
  - Lehman, Hon. William, a Representative in Congress from the State of Florida, opening statement of ..... 6
- Miller, Hon. George, a Representative in Congress from the State of California, and chairman, Select Committee on Children, Youth, and Families:
  - AIDS and Young Children in South Florida (a fact sheet) ..... 3
  - Letter to Ana Garcia, M.S.W., dated October 2, 1989 ..... 112
  - Letter to Deanna James, M.D., dated October 2, 1989 ..... 110
  - Letter to Gwendolyn Scott, M.D., dated October 2, 1989 ..... 108
  - Letter to Margaret Oxtoby, M.D., dated October 2, 1989 ..... 103
  - Opening statement of ..... 2

BEST COPY AVAILABLE
4

Page

Prepared statements, letters, supplemental materials, et cetera—Continued
- Miller, Rev. Dr. Roger P., chaplain in AIDS ministry, University of Miami/Jackson Memorial Medical Center, Miami, FL, prepared statement of ..... 76
- Oxtoby, Margaret, M.D., Centers for Disease Control, Public Health Service, U.S. Department of Health and Human Services, Washington, DC, prepared statement of ..... 11
- Plummer, Phil, administrator, South Florida AIDS Network, Jackson Memorial Hospital, Miami, FL, prepared statement of ..... 54
- Scott, Gwendolyn B., M.D., pediatrician, and professor of pediatrics, Division of Pediatric Infectious Disease and Immunology, University of Miami, School of Medicine, Miami, FL, prepared statement of ..... 20

# AIDS AND YOUNG CHILDREN IN SOUTH FLORIDA

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## MONDAY, AUGUST 7, 1989

House of Representatives,
Select Committee on Children, Youth, and Families,
*Washington, DC.*

The select committee met, pursuant to notice at 10:08 a.m., at the University of Miami, Jackson Memorial Medical Center, Mailman Center for Child Development, Auditorium 8th floor, 1601 NW. 12th Street, Miami, FL, Hon. George Miller, presiding.

Members present: Representatives Miller, Lehman, and Durbin.

Staff present: Ann Rosewater, staff director; Karabelle Pizzigati, professional staff, and Carol M. Statuto, minority deputy staff director.

Chairman **Miller**. The Select Committee on Children, Youth, and Families will come to order, for the purpose of conducting a hearing this morning on AIDS among young children in Florida. And I want to begin by thanking my colleague and Senior Democrat on this committee, Congressman Bill Lehman for the invitation to come here to discuss this very, very troublesome subject matter and for all of the help that he and his office have given in arranging this hearing for this Select Committee.

I would also like to thank the University of Miami, Jackson Memorial Center and the Mailman Center for their support for this hearing. I would have to say that Jackson Memorial Hospital has been a major contributor, if you will, to the body of knowledge of the Select Committee over its six years of existence, they have helped us make some public policy decisions with respect to health care for children and to other emerging problems that we have witnessed in this country, they have also shown us in hearings and in evidence presented to this committee some of the ways that we can avoid not only the tragic cost of uncared for children and families, but some of the very real financial costs to our society by not providing first class care at the right times, but rather a lot of remedial care later on in the process.

This hearing on AIDS in young children was one of the most difficult subject matters that this committee has undertaken. It was extremely hard to see these children and to talk to their families; to talk to those who are providing care and to see these victims who really essentially are the smallest victims—the littlest victims of our failing war on drugs and our failed policy with respect to drugs in this country, to hear, as we will this morning, testimony of care givers that are stretching every conceivable resource to try to provide help both to the children and to their families. This story is not terribly different than in other areas of this country where the Select Committee has heard testimony; where we have listened to individuals talk about trying to find sufficient resources, not only to treat the infected babies, but also to try to stem the tide of children born with AIDS.

This is a problem that, considering the numbers, is going to continue to rush at the Congress. It is going to be expensive. It is going to be difficult and it is going to have to be long term. This is not something that is going to be remedied with slogans or one-year political campaigns. This is going to require a sustained effort on behalf of the Federal Government.

[Statement of Hon. George Miller follows:]

### OPENING STATEMENT OF HON. GEORGE MILLER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA, AND CHAIRMAN, SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

The Select Committee on Children, Youth, and Families has come to Miami today to address the rising tide of AIDS among Florida's infants and young children. It is especially noteworthy that the Select Committee is in Florida to continue its investigation, begun three years ago, for this State has just climbed into second place, behind New York, with its tragically high number of reported cases of childhood AIDS.

Let me give special thanks to my colleague on the Select Committee, Congressman William Lehman, the ranking Member of our Committee and a long-time advocate for children in Congress and in this State. Without his invitation and assistance, we would not be in Miami today.

I would also like to thank the University of Miami Jackson Memorial Medical Center for hosting the Select Committee once again and for their commitment and compassion in treating Florida's most vulnerable babies.

During the last decade, AIDS has emerged as one of the most serious public health threats of our time. It is commonly perceived, however, that the AIDS epidemic has stabilized. But as Florida most powerfully demonstrates, for mothers, and all too often their babies, this is not the case. In Florida this year, 1,000 women infected with the AIDS virus will give birth, and as many as half of their newborn children will develop AIDS before their fifth birthday.

Nationally, the escalation for children is so rapid, that in less than three years, at least 10,000 to 20,000 children will be HIV-infected. Forty percent of all pediatric AIDS cases were reported in 1988 alone.

These babies are the littlest victims of our failing war on drugs, which daily provides an ever-expanding pool of drug-exposed infants at great risk of having the AIDS virus. A recent Select Committee survey found a three- to fourfold increase in drug exposure among newborns in major metropolitan hospitals across the country. Public health experts project that more than 10,000 substance-exposed infants will be born in Florida this year.

Minority children are without question the hardest hit by this onerous virus, with more than three-fourths of all childhood AIDS cases affecting Black and Hispanic children, and an even greater percentage in Florida. Already at greater risk for poverty and poor health, these children bear the brunt of failing policies and insufficient resources and attention.

As tragic and costly as this epidemic has been, there is some light at the end of the tunnel. At our first hearing on infants born with AIDS and drug addiction in 1986, James Oleske, a pediatrician from Newark, New Jersey, warned us that abandoning these children to certain rapid death was a serious mistake and lamentable policy. He has since documented that providing a comprehensive and compassionate course of care results in more and better days of life than we might ever have expected for these children.

Today we will learn about other advances in medical care and social supports that provide hope and new opportunities for improving these children's life chances. We will also hear from noted pediatric AIDS researchers, clinicians and community leaders from South Florida and communities such as Miami and Belle Glade that have been heavily affected.

Welcome. I look forward to the testimony we will hear today.

## AIDS AND YOUNG CHILDREN IN SOUTH FLORIDA

*A FACT SHEET*

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### AIDS AMONG TOP TEN CAUSES OF CHILD DEATHS

- AIDS ranks as the ninth leading cause of death among children ages 1 to 4, and seventh in young people ages 15 to 24. If current trends continue, AIDS will move into the top five causes of death in the next three or four years. (Secretary's Work Group on Pediatric HIV Infection and Disease, U.S. Department of Health and Human Services [HHS], November 1988)

- As of June 1989, there were a total of 99,936 reported AIDS cases in the U.S. Of that number, 1,681 involved infants and children under age 13. (Centers for Disease Control [CDC], July 1989)

- The number of pediatric AIDS cases has increased steadily over the past 5 years, with 85% of the cases reported since 1985. 40% of the pediatric AIDS cases were reported in 1988. (DHHS, Health Resources and Services Administration [HRSA], July 1989)

- For every child who actually has AIDS, another 2-10 children are estimated to be HIV-infected. By 1991, it is estimated that at least 10,000-20,000 U.S. children will be HIV-infected. (HHS, November 1988)

### AIDS CASES FOR FLORIDA'S CHILDREN AND ADULTS AMONG NATION'S HIGHEST

- Florida, with 8,019 AIDS cases reported, ranks third nationally in the total number of AIDS cases reported, behind New York (23,030) and California (19,821). Of these states, Florida has seen the greatest increase in the rate of infection, up 56% in the past two years. (CDC, July 1989)

- Florida has the second highest number of reported pediatric AIDS cases (215), following New York (500). The city of Miami alone has seen 105 reported pediatric AIDS cases. (CDC, July 1989; Dade County AIDS Surveillance, HRS, July 1989)

- In a study of 50-60% (11,588) of Dade county babies born between July and December 1988, 102 newborns tested positive for HIV antibodies, suggesting that 170-200 babies were born HIV-positive during this period. (Florida Department of Health and Rehabilitative Services [Florida HRS], May 1989)

## MINORITY CHILDREN HIT HARDEST BY AIDS

- Black children constitute 15% of the nation's children, yet account for 53% of all childhood AIDS cases. Hispanic children, who represent 10% of U.S. children, account for 23% of all pediatric AIDS cases. (CDC, July 1989)

- Eighty-seven percent of Florida pediatric AIDS cases involve minority children (80% black and 7% Hispanic). In Dade County, 91% of the pediatric AIDS cases involve black children and 7% Hispanic children. (Florida HRS, May 1989; Dade County AIDS Surveillance, HRS, July 1989)

## HIV INFECTION PROMINENT IN FLORIDA HETEROSEXUAL COMMUNITY

- Nationally, 29% of all reported AIDS cases involve heterosexual persons, compared with 41% of all reported AIDS cases in Florida and 47% of cases in Dade County. (CDC, July 1989; Florida HRS, May 1989)

- While women represent approximately 9% of reported AIDS cases in the U.S., they represent 12% of reported cases in Florida. (CDC, July 1989; Florida HRS, July 1989)

## MORE AND MORE NEWBORNS AT RISK

- Over 75% of AIDS cases in children result from perinatal transmission. Pediatric AIDS specialists estimate that 30-50% of infants born to HIV-infected women will be HIV-infected. (CDC, 1989; Association for the Care of Children's Health [ACCH], 1989)

- Nearly 1,000 women infected with the AIDS virus will give birth in Florida in 1989, and 300 to 500 of their newborn children will develop AIDS before their fifth birthday. (Florida HRS, March 1989)

- Of children who became infected perinatally, 73% have mothers who are either IV drug users or the sexual partners of IV drug users. A recent 15-city survey found a three to four fold increase in drug exposure among newborns in major metropolitan hospitals. (HRSA, July 1989; Select Committee on Children, Youth, and Families, 1989)

- In Florida, a 1986 statewide survey of 25 hospitals with neonatal units revealed that as many as 5,000 babies were born with symptoms or evidence of drug, primarily cocaine, exposure. Estimates indicate that over 10,000 substance-exposed infants will be born in Florida this year. (Coler, July 1989)

## PEDIATRIC AIDS BURDENS HEALTH CARE SYSTEM

- By 1991, one out of ten U.S. pediatric beds may be occupied by an HIV-infected patient. (HHS, November 1988)

- Treatment and support services for an eligible perinatally-infected infant can be expected to cost Medicaid from $18,000 to $42,000 per year. In Florida, the average annual health care cost in 1986 for children with HIV-related diagnoses was approximately $20,000. (HHS, November 1988)

## TREATMENT OF PEDIATRIC AIDS CAN MAKE A DIFFERENCE

- The provision of comprehensive care services to children with AIDS has decreased the immediate mortality rate from 65% to 35%, reduced the average hospitalizations from 2-3 per year to 1-2, and cut in half the average length of stay from 30 to 14 days. (Oleske, Children's Hospital, Newark, NJ, personal communication, 1989)

- A study of 21 pediatric AIDS cases found that the continuous infusion of AZT produces significant improvements in appetite, weight gain, and neurologic development of the children, including better IQ scores and adaptive behavior. (Pizzo, October 1988)

- The life expectancy of an HIV-infected infant varies. Many children who show symptoms before the age of 2 die within a year of diagnosis. Other children do not become sick until they are 5 or 6, and with aggressive medical treatment, may live for a number of years. (ACCH, 1989)

8/7/89

Chairman Miller. And I want again to just thank everybody here for their participation in helping us to deal with this subject matter and hopefully help us as we make policy decisions in Washington, DC. Again, my thanks to Congressman Bill Lehman. And, Bill, I would like to recognize you for any statement you may have.

Mr. Lehman. Thank you, Mr. Chairman. I have a statement, which I ask unanimous consent that it be accepted in full for the committee record.

Chairman Miller. Without objection, so ordered.

Mr. Lehman. And I will summarize it. I want to thank you and our colleague from Illinois, Richard Durbin, for being here. You have your own problems in your own Districts, your own concerns in your own Districts and we appreciate here that you are taking time out to deal with the problems that we have here.

I want to thank Ira Clark for helping us set up this meeting and being able to bring the panels together so that we can help deal with some of the problems facing this community.

This is not a local problem. AIDS is a massive problem, but this community in particular faces intense problems with AIDS, especially in relation to AIDS in newborn babies.

This year the number of AIDS patients will double, the number of AIDS patients in children will double. As I said, AIDS is not a local problem, it is a national problem, but because of the integration of Miami and the Jackson Memorial Hospital, a key treatment center and a research center, we have to deal with the AIDS problem at a local level and what we are going to do here can be applied nationally.

A couple of statistics, Florida now is number two of all the States in the number of AIDS cases and half of those are right here in Miami. And also, although it is known as number two in gross numbers, in the rate of growth of AIDS cases, it is now number one in the whole United States.

It is truly a public health problem, and cuts across the board. At the present time there are 258 cases in the State of Florida that deal with children. And I think that this is, as the Chairman said, the most tragic aspect of AIDS as it affects these tiny innocent victims.

We have two problems with AIDS. One of the problems of course is financial, but even more is the problem of compassion for the victims, the unfortunate victims, especially the small ones that are infected with the problem of Immune Deficiencies Syndrome.

I am sure though the community will benefit from the insight and the experience of our distinguished panelists and we can take back to Washington to deal with, at the Federal level, in whatever way that we can to alleviate the intensity of this situation.

### Opening Statement of Hon. William Lehman, a Representative in Congress From the State of Florida

Mr. Chairman, I want to welcome you and the other members of our committee to Miami. Thank you for coming here today.

This is not the easiest place to visit in the middle of summer. I think the fact that you came to Miami in August is a strong indication that you attach the same importance as I do to the massive problems this community faces because of AIDS, particularly AIDS in babies. I'm told that the number of children with AIDS in Dade County is expected to double this year alone.

Some people believe that the AIDS epidemic is a local problem, that the federal government does not have responsibility in this area. I think that viewpoint is wrong, and dangerous. We heard the same talk about the drug epidemic, when drug abuse was primarily a problem of inner cities. Now polls show most people think drugs are one of our most serious problems. I think the same is true for AIDS. The warning signs are plain. We simply cannot afford to ignore them.

One of the reasons I invited the Committee here in the first place is because we are fortunate to have so many experts on various aspects of the AIDS problem. Many of these people have national reputations in their fields. I suggested we meet here at the Mailman Center because the University of Miami/Jackson Memorial Hospital is a key AIDS treatment and research center.

A quick review of a few statistics helps explain why there is so much expertise in S. Florida on the AIDS problem: Florida has the second highest number of pediatric AIDS cases of any state in the country; about half of these cases are in the City of Miami alone; Florida ranks No. 1 of all the states in the rate of increase of AIDS infections, and No. 1 of all the states in the number of heterosexual AIDS cases. In fact, in Dade County almost half of the AIDS cases involve heterosexuals. This last statistic shows that AIDS is truly a public health problem in the broadest sense of the word.

But nowhere is AIDS more tragic than when it affects children—the most innocent and vulnerable in our society. At present, the numbers aren't great—215 pediatric AIDS cases in the State of Florida, compared with over 8,000 cases of AIDS in adults—but that number is expected to double this year alone. And these babies have an enormous impact on health care and social services that is disproportionate to their numbers.

I would like people in our community and decision makers in Washington to know more about this problem—its extent, its growth, what it does to children and families, the impact it has on health care and social services in our community, how much it costs us in both human and economic terms, and who ends up paying.

The experts tell us that the problems facing Dade County today are going to face many other communities in just a few years. Government leaders all over the country are looking to us to see how to handle the AIDS epidemic.

I am confident that the committee will benefit from the insight and experience of the distinguished panel of witnesses we will hear from today.

Chairman MILLER. Thank you, and I would also like to introduce and to recognize, Congressman Richard Durbin, who is a member of the Appropriations Committee, as is Chairman Lehman, of the House of Representatives, and also a member of the Select Committee, who has been very much involved in the health problems of young children with this committee. Dick?

Mr. DURBIN. Thank you, Chairman Miller and my colleague Bill Lehman.

As George Miller has indicated, I serve on both the Appropriations and Budget Committees, in addition to this Select Committee. I would have to tell you that of the three committee assignments, this may be the most thought provoking. Each week we consider new issues in Washington that relate to the future of America. That relate directly to the children, youth and families of America.

Today and this morning we will address the emergency of a generation of new Americans. New Americans who are unfortunately the tragic victims of today's society. These kids have been handicapped by new problems, new diseases, new addictions. They are infants victimized by AIDS and in other hearings we have considered their counterparts, victimized by cocaine addiction, fetal alcohol syndrome and so many other problems.

These children who should be our hope, now have emerged as a troubled legacy of today's America. We will consider of course this morning, education, prevention, treatment, but most of all I hope we emerge with an understanding of what we are dealing with in terms of not only a problem here in Southern Florida, but a national challenge as well.

I want to say in conclusion here, that I particularly want to salute my colleague Bill Lehman for his caring, thoughtful and effective leadership in the House of Representatives. Miami, Florida and the nation is fortunate to have Bill's representation and I look forward to this hearing.

Chairman MILLER. Thank you. We are going to hear from two panels this morning. The first will be made up of Dr. Margaret Oxtoby, who is the Chief of Pediatric and Family Studies Section from the AIDS Program for the Centers for Disease Control of Atlanta, Georgia; Dr. Gwendolyn Scott, who is Professor and Acting Director of Pediatric Infectious Disease and Immunology, University of Miami School of Medicine; Dr. Deanna James, who is the Medical and Executive Director of the C.L. Brumbeck Community Health Center in Belle Glade; and, Ana Garcia, who is the Associate Coordinator of the University of Miami Pediatric AIDS Demonstration Project, Department of Obstetrics and Gynecology from Miami, Florida.

If you will come forward, we will take your testimony in the order in which we have called your name. Your written statements will be made a part of this record in their entirety. The extent to which you want to summarize or highlight, please feel free to do so. And welcome very much to the committee and we thank you for taking your time and your trouble to make your presentation here today. And we want you to know how much we appreciate it. Dr. Oxtoby, we will start with you.

## STATEMENT OF MARGARET OXTOBY, M.D., CHIEF, PEDIATRIC AND FAMILY STUDIES SECTION, AIDS PROGRAM CENTERS FOR DISEASE CONTROL, ATLANTA, GA

Dr. OXTOBY. Thank you. Mr. Chairman, and members of the committee, I am Margaret Oxtoby, Chief of the Pediatric and Family Studies Section in the AIDS Program, Centers for Disease Control and I am pleased to represent C.D.C. in briefly discussing our efforts to prevent HIV infection in children and youth.

First, I would like to provide some background information about the epidemic. By early July about 100,000 cases of AIDS had been reported to C.D.C. Of this total number of 100,000, approximately 1,700 or 2 percent were in children less than 13 years of age. Another 400 were in adolescents.

Approximately 4,000 AIDS cases, 4 percent of all cases, were diagnosed among those aged 20 to 24, and 16,000 were diagnosed among those 25 to 29 years old. All together 20 percent in that young adult group. Because the average incubation period from HIV infection to AIDS is eight to ten years, many of those young adults diagnosed in their 20's most likely were infected with HIV as adolescents.

The first cases of pediatric AIDS were reported in 1982, about one year after the initial adult cases were reported to C.D.C. We project that by 1991, over 3,000 AIDS cases among children will have been reported, with over 1,000 in 1991 alone.

In addition, some children will develop other HIV-related illnesses that do not meet the current criteria, but these children will still require intensive medical attention.

So, therefore the reported cases under represent the extent of illness in this age group. Based, however, on reported cases alone, pediatric AIDS is already the ninth leading cause of death among children one to four years of age, and the seventh in young people between the ages of 15 and 24, and is increasing rapidly in comparison with other causes of death.

Mother-to-child transmission of HIV, during pregnancy, delivery, or through breast feeding, accounts for three-quarters of all of the children reported with AIDS. And this problem of mother-to-infant transmission is likely to increase, since in cases reported before 1984, 7 percent were in women, and currently over 10 percent of all cases are among women.

Of children born to infected mothers, approximately a third will become infected with HIV. The mothers of these children, about slightly over half, are women who have used IV drugs, and most of the remainder were probably infected through sexual contact with an infected partner.

It should be noted that children can also be infected through contaminated blood products, but this risk has been now virtually eliminated in the United States. Other possible modes of transmission include sexual abuse.

Although AIDS cases in children have been reported from nearly all States, 55 percent of cases come from New York, New Jersey and Florida, primarily from the large urban areas. And three out of four children with AIDS are Black or Hispanic.

I would like briefly to mention the ways in which C.D.C. is addressing the problems of pediatric HIV infection. First, through surveillance for HIV. National surveillance for AIDS cases is conducted in all States and Territories. In addition, C.D.C. is conducting expanded surveillance for all HIV infection, in several geographic areas, to define better the extent of the problem in this population. And lastly, C.D.C. is supporting HIV seroprevalence surveys in neonates in nearly 40 States and also in young children attending outpatient clinics in several cities, including Miami.

The National Institute of Child Health and Human Development also funds neonatal surveys in an additional five States. In Florida, results from the first 60,000 neonatal samples tested, showed that 293, or .5 percent, were positive for HIV, meaning that one in every 200 women bearing children was infected with HIV.

Based on preliminary data, we anticipate that over 5,000 women in the United States, nationally, who are infected are bearing children, and of those children 1,500 or 2,000 would be infected.

C.D.C. is supporting several perinatal research projects, which are seeking to define risk factors for transmission to evaluate new tests for diagnosis of HIV and assess the effect of pregnancy on HIV; also to describe better the course of disease in infants, and the children in these studies will be entered in NIH sponsored treatment trials whenever possible.

Lastly, C.D.C. supports a number of HIV prevention activities. First, perinatal AIDS prevention projects include activities designed to encourage the effective use of contraception among HIV infected women, and women at high risk of infection who wish to avoid pregnancy. Eight of these projects were directly funded by C.D.C., starting in 1988, and are expected to be expanded this year to cover other areas with the highest potential for HIV infection among women.

The projects seek to determine and to overcome obstacles to effective use of contraception in the various populations at highest risk for HIV. And two of these projects are in South Florida:

C.D.C. has also worked closely with the Office of Population Affairs to include HIV prevention training in programs carried out by Title X Family Planning Regional Training Centers. Over 4 million sexually active women visit federally funded family planning clinics each year, but many of the staff working in these clinics have lacked the skills and knowledge to provide appropriate HIV-related services.

In addition to those perinatal HIV prevention efforts, C.D.C. established in 1987, a program to help schools and other agencies that serve youth to implement effective education to help young people avoid risks for HIV infection and to deal with other important health problems. The schools are a particularly important focus for HIV prevention, since more than 45 million young people are enrolled in elementary and secondary school and 12 million in colleges and universities.

The C.D.C. program integrates several systems to enable schools and organizations that serve youth not in school, to implement effective AIDS educational strategies that are consistent with community values and needs.

Lastly, to reach the general public, C.D.C. initiated a national information campaign in 1987, with the theme "America Responds to AIDS", to give visibility and national significance to actions that will prevent HIV infection. This year, C.D.C. launched the "Parents and Youth" phase of the advertising campaign. And this phase is designed to facilitate communication between parents and youth and their children, regarding HIV prevention. These efforts are being implemented together with national youth and educational organizations and State educational agencies.

The C.D.C. continues to work together with other Federal agencies in response to the epidemic. In 1988, the former Health and Human Services Secretary, Otis Bowen, established a Workgroup on Pediatric HIV Infection and Disease, which was chaired by Dr. Antonio Novello of NICHD, and was composed of representatives from all major elements of the Department, including Family Support Administration, Office of Human Development Services, Health Care Financing Administration, Social Security Administration and the Public Health Service. This workgroup made a number of recommendations in the areas of research, care, prevention and financing and we hope to continue to work, or mark progress toward carrying out these work group recommendations.

Thank you.

[Prepared statement of Margaret Oxtoby, M.D., follows:]

## Prepared Statement of Margaret Oxtoby, M.D., Centers for Disease Control, Public Health Service, U.S. Department of Health and Human Services, Atlanta, GA

Mr. Chairman and Members of the Committee:

I am Margaret Oxtoby, Medical Officer, Centers for Disease Control, and I am pleased to represent CDC in discussing our efforts to prevent HIV infection and AIDS in children and youth.

First, I would like to provide background information about the problem of HIV infection and AIDS in the pediatric population.

Although most of the attention in pediatric AIDS has been focused on infants and younger children, HIV infection is also a significant problem for the older "pediatric" population, i.e., adolescents who may be sexually active or using intravenous (IV) drugs. For these purposes, we will discuss the range of CDC activities directed towards children as well as adolescents.

As of June 30, 1989, 99,936 cases of AIDS had been reported to CDC. Of this total number, 1,681 (approximately 2 percent) were in children less than 13 years of age; another 389 were in adolescents 13-19 years of age. An additional 4388 AIDS cases (4 percent of all cases) were diagnosed among those aged 20-24, and 16,157 cases (16 percent of all AIDS cases) were diagnosed among those 25-29 years-old. Because the average incubation period from infection with HIV to the development of AIDS is 8-10 years, many of the young adults 20-29 years of age most likely were infected with HIV as adolescents. Pediatric AIDS is already the ninth leading cause of death among children 1 to 4 years of age, and the seventh in young people between the ages of 15 and 24, and is increasing rapidly in comparison with other causes of death.

The issues of AIDS in children less than 13 years of age are very different from those related to adolescents. Therefore, I will consider these two groups separately.

The first cases of pediatric AIDS were reported in 1982, about one year after the initial adult cases of AIDS were reported to CDC. CDC projects that by 1991, over 3000 cases among children will have been reported, with over 1000 reported in calendar year 1991 alone. An additional, but unknown, number of children will develop HIV-related illnesses that do not meet the currently defined criteria for AIDS, but will still require intensive medical attention. Therefore, reported AIDS cases underrepresent the extent of significant HIV-related illness in the pediatric age group. Pediatric AIDS is already the ninth leading cause of death among children 1 to 4 years of age, and the seventh in young people between the ages of 15 and 24, and is increasing rapidly in comparison with other causes of death.

Children may be infected with HIV by congenital or perinatal transmission from mother to child during pregnancy, during delivery, or following birth through breast feeding. The problem of mother-to-infant transmission is likely to increase because the proportion of female AIDS cases has risen from 7 percent reported prior to 1984 to 10 percent in 1988. Approximately 25 to 50 percent of the infants born to HIV-infected mothers will become infected with HIV. Over 75 percent of AIDS cases in children result from perinatal transmission. Of this group, 73 percent of the mothers were intravenous (IV) drug users or were sexual partners of IV drug users. Children also can be infected through transfusions of blood or blood products, although this risk has now been virtually eliminated in the U.S. Other possible modes of transmission include sexual abuse.

Although AIDS cases in children have been reported from 45 States, Washington, D.C., Puerto Rico and the Virgin Islands, 55 percent of cases come from New York, New Jersey and Florida, primarily from large urban areas. Three out of four children (75 percent) with AIDS are black or Hispanic.

CDC is addressing the problem of pediatric HIV infection and related disease in several ways including surveillance, and research in modes of transmission, diagnosis, and natural history.

Surveillance for pediatric HIV disease is being conducted through ongoing surveillance for AIDS cases in all States and territories, expanded national surveillance of HIV infection and AIDS in infants and children, including CDC-funded surveillance for HIV infection in six selected geographic areas (states or cities) to define better the extent of the problem in this population, and through HIV seroprevalence surveys in neonates in nearly 40 States and in young children attending outpatient clinics in the cities of New York, Washington, D.C., and Miami. The National Institute of Child Health and Human Development funds neonatal surveys in an additional five States (Maine, Massachusetts, New Hampshire, Rhode Island and North Carolina). In Florida, results from the first 60133 neonatal samples tested showed that 293 (0.5%) were positive for HIV, meaning that 1 in every 200 women bearing children in Florida is infected with HIV.

Ongoing research studies in New York and Newark of children born to HIV-infected mothers will attempt to define risk factors for transmission of HIV from mother to child, evaluate new tests for diagnosis of HIV in infants, assess the effects of pregnancy on the course of HIV disease and the effects of HIV infection on pregnancy complications and outcomes and describe better the course of the disease in infants. The children in these studies also will be entered into NIH-sponsored treatment trials whenever possible. Another study, being conducted in a south Florida community that has a high prevalence of HIV, will evaluate the sexual and reproductive behavior of women, with the goal of developing possible approaches for supporting behavior change to reduce the risk of infection in these women and their children.

CDC-funded Perinatal AIDS Prevention Projects include activities designed to encourage the effective use of contraception among HIV-infected women and women at high risk of infection who wish to avoid pregnancy. Eight Perinatal AIDS Prevention Projects were directly funded by CDC in fiscal year 1988 and will continue to be supported in fiscal year 1989. These projects will: 1) determine, and seek to overcome, obstacles to effective use of contraception in target populations; 2) facilitate the use of family planning services by these women; 3) evaluate attitude factors related to the use of contraception among HIV-infected and high-risk women; and 4) encourage behavioral change among HIV-infected and high-risk women to reduce risk of HIV infection. Perinatal AIDS Prevention projects are expected to be expanded in 1990 to cover the approximately 20 areas with the highest potential for HIV infection among children.

CDC has also worked closely with the Office of Population Affairs (OPA) to include HIV prevention training in programs carried out by Title X Family Planning Regional Training Centers. Over 4 million sexually active women visit federally funded (Title X) family planning clinics each year, but many of the staff working in these clinics have lacked the skills and knowledge to provide appropriate HIV-related services. In addition, CDC continues to provide technical assistance and consultation to OPA on a variety of women's health issues, including HIV.

In addition to the perinatal HIV prevention efforts discribed above, in fiscal year 1987, CDC established a program to help schools and other agencies that serve youth nationwide implement effective education to help young people avoid risks for HIV infection and to deal with other important health problems. The schools are a particularly important focus for HIV prevention efforts since more than 45 million young people are currently enrolled in some 90,000 elementary and secondary schools across the country and more than 12 million additional students are enrolled in colleges and universities. The CDC program integrates several systems to enable schools and organizations that serve youth not in school to implement effective AIDS educational strategies that are consistent with community values and needs.

To reach the general public, CDC initiated a national information campaign in fiscal year 1987 with the theme, "America Responds to AIDS." The campaign was designed to: (1) give national significance and visibility to actions that will prevent HIV infection; (2) reach both the general population and special targeted groups, and (3) develop strategies that will be used in the future.

In May 1989, CDC launched the "Parents and Youth" phase of its multi-media public service advertising campaign. This phase is designed to facilitate communication between parents and their children regarding HIV prevention. These efforts are being implemented in close collaboration with national youth and educational organizations and State education agencies.

The Centers for Disease Control continues to work closely with other federal agencies in efforts to respond to the HIV epidemic. In 1988, the former DHHS Secretary Otis Bowen established a Workgroup on Pediatric HIV infection and disease. The workgroup was chaired by Dr. Antonia Novello of NICHD, and was composed of representatives from all major elements of the Department: the Office of the Secretary, the Family Support Administration, the Office of Human Development Services, the Health Care Financing Administration, the Social Security Administration, and the Public Health Service. This workgroup established priorities in the areas of research, care, prevention, and financing. We hope to continue to mark progress toward carrying out the workgroup recommendations.

Thank you. I will be happy to answer questions.

WP#63/07/28/89

Chairman MILLER. Thank you. Dr. Scott.

## STATEMENT OF GWENDOLYN SCOTT, M.D., PROFESSOR AND ACTING DIRECTOR, PEDIATRIC INFECTIOUS DISEASE AND IMMUNOLOGY, UNIVERSITY OF MIAMI SCHOOL OF MEDICINE, MIAMI, FL

Dr. SCOTT. I would like to thank you very much for this opportunity to testify before your committee about AIDS in children.

My name is Dr. Gwendolyn B. Scott. I am a pediatric infectious disease specialist and a Professor of Pediatrics at the University of Miami School of Medicine.

I have been working with HIV-infected children since 1981, and I direct the Clinical Care and Research in this group of children at Jackson Memorial Hospital and the Children's Hospital Center in Miami, Florida.

Today, I would like to update you on information about AIDS in children, particular in South Florida. As Dr. Oxtoby told you, the first cases of AIDS in children were reported in 1983. And since that time, approximately 1,600 cases of AIDS in children have been reported to the C.D.C.

However, I think it is important to recognize that HIV infection in children represents a broad spectrum of disease and AIDS is the severe end of the spectrum. So that the actual number of infected children are underestimated. And I would estimate that perhaps is for every child who is perinatally infected, that there may be two or three additional infants who have not been identified through the surveillance system.

In Miami we have now diagnosed 266 HIV-1 infected children at our medical center between January 1981 and June 30, 1989. One hundred and twenty three of those children meets the C.D.C. definition for AIDS, and 62 percent of those children with AIDS have died.

The population that we see, 83.8 percent are Black, 7.5 percent are Hispanic, and 8.6 percent are White. We currently diagnose one new case per week and we are actively following about 140 infected children. And almost all of these children have been identified because of the presence of symptomatic disease.

We know that case reports of AIDS in children have been received from many States in the Union, however, Florida ranks second in terms of number of pediatric cases reported. There are 215 cases reported in Florida, under age 13, and 38 in the 13 to 19 year age group. Over 50 percent of those cases to date, have been diagnosed at our clinic in Miami. And when we look at those statistics, over 85 percent of those cases are due to perinatal transmission.

In South Florida the majority of infected children have been residences of Dade, Broward and Palm Beach Counties. Dade makes up 47.9 percent, Broward 8.9 percent, and, Palm Beach 15.5 percent.

In children under 13 years of age, the majority of infection occurs as a result of a transmission from an infected mother to her infant. We do not know exactly the timing of transmission, but we do know that that transmission might occur in utero at the time of delivery, or in a few cases, post-natally by ingestion of infected breast milk.

And I would like to briefly describe those cases, because these were children whose mothers had been transfused after delivery and those mothers, unfortunately, received HIV-infected blood. The mothers then breast fed those infants and unfortunately later, both mother and infants were found to be infected. There are four reported cases at this point in the country, one of those has come from Australia, two from Uganda and I think there is one in the United States at this point.

So, these are very special cases and as far as the role of breast milk in general, breast milk probably does represent a small incremental risk for infection, however, we do not know whether breast milk from all infected mothers, in all stages of disease, can transmit the virus. So that there needs to be a lot more research and studies done on the role of breast milk and transmission of this disease, because we realize that breast milk is essential in many parts of the world for survival.

Infection has occurred also in a high proportion of children with severe hemophilia and in children who received blood or blood product transfusions from an infected donor prior to 1985.

The other area that I consider a huge problem are the adolescent age group. In the 13 to 18 year age group, the mode of transmission is more similar to adults. Approximately 48 percent are homosexual or bi-sexual males; 22 percent have hemophilia or coagulation disorder; 6 percent are from blood transfusion; 6 percent from intravenous drug abuse; and, 3 percent from heterosexual contact.

On the other hand, when you look at female adolescents, a higher proportion of female adolescents who are infected, have been infected because of heterosexual contact. And this is a group that we know very little about. Unfortunately, adolescents do not routinely access medical care systems and we are now beginning to see pregnant adolescents who are HIV-infected, delivering HIV-infected infants. So this is a group where education is essential and they must be aware of how to protect themselves and how this disease is transmitted.

Infected children commonly live in the inner city and come from low socioeconomic backgrounds. National AIDS surveillance data indicate that 52 percent of children are Black; 23 percent are Hispanic; and, 24 percent Caucasian. And as Dr. Oxtoby told you, it is estimated that over 70 percent of perinatal cases can be related to drug abuse in one or both of the parents. However, in Miami this is much different, 65 percent of women giving birth to infected children have become infected through presumed heterosexual transmission.

HIV infection in children is primarily a disease of infants and toddlers. Over 80 percent of cases are cases in children under three years of age, with the majority of those children becoming ill in the first two years of life.

But I think it is important again, to remember that there is a spectrum of disease as some children do survive for longer periods of time with less symptoms. But, because the majority of them do develop disease very early, there may be only a short time period where they are asymptomatic and where drug treatment might be effective in that group.

HIV infection in children differs quite greatly from that in adults. And it stresses the importance of studying the natural history of this disease in children. The rate of perinatal transmission is estimated to be somewhere between 20 and 50 percent. At this point, we do not understand what factors promote transmission of this virus from mother to infant. The spectrum of disease in children is broad and includes developmental delay, progressive central nervous system disease, lung, heart and kidney disease. So it is a multi-system type of infection.

Also we have a very special problem in children, in that the diagnosis is very difficult to make, particularly in the infant because of passive transfer of HIV antibody from the mother to the infant. Most of these infants born to HIV-positive women, are clinically and immunologically normal at birth, they are no different from any other child.

Therefore, the antibody testing cannot, by itself, determine whether or not an infant is infected. In some cases this maternal antibody may persist for many months and the child's HIV status may not be determined until they are 15 or 18 months of age. And you can imagine the trauma that this causes to the parents, not knowing whether or not their child is infected or not.

Chairman **Miller**. Dr. Scott, let me ask you now because I know you have a time problem.

Dr. **Scott**. Okay, all right.

Chairman **Miller**. We were not going to ask you questions.

Dr. **Scott**. Well, I think that if I could then, I think that other important issues are treatment issues. As I said before, identification of these infants is very important, because there is only a short period of time when they are asymptomatic or only mildly symptomatic, so we need access to drugs early for those children and we need to test drugs to concomitantly with the testing that is going on in adults.

Also, I would add that the epidemiology of disease in children, closely parallels that in women. And so it is very important to give women the option for having the test, voluntarily with permission, and this will then help them in knowing their options in terms of pregnancy, the chance for perinatal transmission and will also provide them access to drug treatment programs.

I think that Ms. Garcia is going to summarize for you a lot of the family aspects, that this is a family unit disease and is devastating for not only the child, but the whole family unit.

And in closing, I would say that these children need advocates and they need advocates at all levels and particularly in the Government. And I hope that as we educate and as you become more familiar with HIV infection in children, that you will become those advocates.

Thank you.

[Prepared statement of Gwendolyn Scott, M.D., follows:]

## PREPARED STATEMENT OF GWENDOLYN B. SCOTT, M.D., PEDIATRICIAN AND PROFESSOR OF PEDIATRICS, DIVISION OF PEDIATRIC INFECTIOUS DISEASE AND IMMUNOLOGY, UNIVERSITY OF MIAMI SCHOOL OF MEDICINE, MIAMI, FL

Good morning, my name is Gwendolyn B. Scott. I am a Pediatrician and a Professor of Pediatrics, Division of Pediatric Infectious Disease and Immunology, University of Miami School of Medicine. I have been working with HIV-1 infected children since 1981 and direct the clinical care and research in this group of children at Jackson Memorial Hospital, Children's Hospital Center, in Miami, Florida.

I am here today to provide up-to-date information about this epidemic and its effect on infants, children and adolescents.

### EPIDEMIOLOGY

The first cases of AIDS in children were reported in 1983. The Centers for Disease Control have received reports of 1,681 cases of AIDs in children under 13 years of age and 389 cases in the 13 to 19 year age group as of June, 1989. This number grossly underestimates the actual number of infected children. There is a broad spectrum of clinical illness associated with HIV infection in children. Only the more severe illnesses meet the CDC surveillance definition for AIDS and are reportable cases. Thus, for every one child reported with AIDS, there may be at least two or more children who are clinically symptomatic but do not meet the criteria for the diagnosis of AIDS. In Miami, we have diagnosed 266 HIV-1 infected children at our medical center between January 1981 and June 30, 1989. 123 meet CDC criteria for AIDS: 62% of these children with AIDS have died. 83.8% are black, 7.5% are hispanic, and 8.6% are white. Currently we diagnose one new case per week and are actively following about 140 infected children. Almost all of these children have been identified because of the presence of clinical disease.

Preliminary findings from 6 months of anonymous testing of blood from newborn infants in Florida showed an overall seroprevalence of 4.9/1000 with the highest seroprevalence in Palm Beach (11.5/1000), Dade (8.7/1000) and Broward (8.4/1000). In this study, Black child bearing women state-wide were 9 times more likely to be HIV infected than White child bearing women.

In a recent survey in Jackson Memorial Hospital by Dr. Mary Joe O'Sullivan, overall seroprevalence in 11,803 pregnant women tested for HIV antibody with their consent was 2.1%. 7.3% of the seropositive women were adolescents. It is noteworthy that in this study 38% of the women did not identify themselves as being at risk.

Case reports of AIDS in children have been received from 44 states, the District of Columbia and Puerto Rico, but the majority reside in New York, Florida, New Jersey and California. Pediatric AIDS is largely a disease found in large coastal metropolitan areas and 55% of cases are reported from New York City, Miami, and Newark. Florida ranks second in the number of pediatric cases reported. In Florida there are 215 children reported under age 13 and 38 in the 13-19 age group. Over 50% have been diagnosed at our clinic in Miami. In South Florida, the majority of infected children have been residents of Dade, Broward and Palm Beach counties.

In children under 13 years of age, the majority of infection (78%) occur as a result of transmission from an infected mother to her infant. An infected mother may transmit the virus to her infant across the placenta during pregnancy, at the time of delivery or postnatally by ingestion of infected breast milk. The actual time during which infection occurs in not known. The majority of HIV-1 infected infants are clinically normal at the time of delivery, which suggests that most infants are likely infected during late gestation or during delivery from exposure to mother's infected blood. Transmission of the virus via breastfeeding has not been studied extensively, but the virus has been cultured from a small number of specimens of breast milk. There are four reported cases that strongly suggest transmission of the virus by breastmilk to an infant. In each case, the mothers were infected after delivery by blood transfusion. These mothers breastfed their infants and subsequently both the mothers and their infants were found to be infected. These mothers however may represent a special group since they were infected shortly before beginning breast feeding. We do not know whether breast milk from all infected mothers in all stages of disease can transmit the virus. Since breast milk is essential in many parts of the world for survival, this needs to be investigated further.

Infection has also occurred in a high proportion of children with severe hemophilia and in children who received blood or blood product transfusions from an infected donor prior to 1985. In the 13 to 18 year age group, the mode of transmission is more similar to adults. Approximately 48 percent are homosexual or bisexual males, 22 percent have hemophilia or a coagulation disorder, 6 percent are from blood transfusion, 6 percent from intravenous drug abuse, and 3 percent from heterosexual contact. We do not know how many adolescents might be infected--even in areas of high prevalence. This is a group where education is essential and they must be aware of how this disease is transmitted.

Infected children commonly live in the inner city and come from low socioeconomic backgrounds. National AIDS surveillance data indicate that 52 percent of children are Black, 23 percent are Hispanic, and 24 percent Caucasian. It is estimated that about 70 percent of perinatal cases can be related to drug abuse in one of the parents However, in Miami 65% of women giving birth to infected children have become infected through heterosexual transmission.

HIV infection in children is primarily a disease of infants and toddlers. Over 80 percent are cases in children under 3 years of age with the majority of children becoming ill in the first two years of life. The sex distribution in children under 13 is equal, but in adolescents, the ratio is 7:1 male to female as compared to 14:1 in adults.

Unfortunately, the prognosis for HIV infected children is grim. The proportion of children with AIDS who die is high and national statistics suggest that once a child is diagnosed with AIDS, the median survival is less than one year. The majority of deaths in this illness occur in the first two years of life. There are a few children with long term survival, but many of these eventually develop disease and have significant morbidity and mortality despite longer survival.

## CLINICAL PICTURE

HIV-1 infection in children differs from that in adults and stresses the importance of studying the natural history of this disease in children. It is estimated that 20 to 50% of infants born to HIV-1 infected mothers will be themselves infected. It is not understood what factors promote transmission of the virus from mother to infant. The spectrum of disease in children is broad and includes developemental delay progressive central nevorous system disease, lung, heart disease and kidney disease.

Making a diagnosis of disease in infants is more difficult than in an adult due to passive transfer of antibody from mother to infant. Therefore, antibody testing cannot immediately determine if an infant is infected. In some cases this maternal antibody may persist for several months and the child's HIV status may not be determined until 15 or 18 months of age. A definitive diagnosis of HIV infection under 15 months of age can only be made by the presence of clinical illness, a positive virus culture, or a positive antigen test. Research efforts need to be directed toward the development of simple laboratory tests for diagnosis in the child less than 15 months of age. Early recognition and diagnosis of infants at risk become important as new therapies are developed. Already it is felt that there is benefit in early recognition of the "at risk" infant.

## TREATMENT

From this information, it is clear that if children are to be saved from the devastation of this disease, infected children must be identified early, preferably before the onset of significant clinical symptoms and treated. Drug treatment in children has lagged behind that of adults. There is no licensed drug available for therapy of HIV-1 infected children under 13 years of age. Phase 1 and Phase II studies with Azidothymidine (Retrovir, AZT) in children and a small Phase 1 study with ribovirin have been completed. Phase I trials of dideoxycytidine (DDC) are ongoing and a phase 1 trial of dideoxyinosine (DD1) is underway. A double blind clinical trial of intravenous gamma globulin with an albumen placebo control is ongoing since November 1987 as part of a Maternal and Child Health Protocol and has enrolled over 200 HIV-1 infected children nationwide.

Placing children on research protocols is a complex issue. Drug studies in children have lagged behind those in adults but the need to gather information on drugs and move into treatment trials is no less urgent. It is also important to gain more information about when and how the infection occurs in perinatal transmission. If infants are infected while still in the uterus, then perhaps even treatment at birth will not be effective and antiviral drug treatment need to be evaluated in infected women in an attempt to prevent disease in their newborn. A phase I protocol using AZT in pregnant women is approved and about to begin.

In addition, new drugs must be made available to children as soon as safety is established so that efficacious drugs will be available for treatment of infected children as well as adults. Since many of these children will come from families who are poor and cannot affod the cost of drugs, it is important that these drugs be made generally available so all children have an equal chance for treatment. This will likely require a large allocation of funds to pay for these treatments. In addition, other obstacles arise in the treatment of children. Some children do not have living parents or legal guardians and permission for treatment of such children can involve long, prolonged and complicated legal procedures. Some parents may have difficulty adhering to strict protocols because of employment, lack of adequate funds for daily living needs or an unfamiliarity with the concept of regular medical care, usually accessing care only in an emergency. Priority should also be given to the development and clinical trials of new antiviral drugs.

## OTHER

Perinatal AIDS is a family unit disease. Frequently the mother does not perceive herself to be at risk and the first evidence of HIV-1 infection in the family is an infected child. Parents may become ill themselves and are no longer able to care for their children, resulting in needs for foster care. Families require a network of services and the care team includes not only medical personnel but social workers, patient advocates, community agencies such as Visiting Nurse Services, Hospice, and other support groups. Adequate financial support is essential and infected children should be eligible for government benefits. The development of respite and day care facilities would assist some families with the chronic care needs of the children.

The epidemic of Pediatric AIDS has created a crisis in pediatric centers faced with growing numbers of cases. There is a need for additional physicians, nurses, social workers and administrative support personnel. In addition, treatment programs and the increase in basic science research has severely impacted on space. Money needs to be made available for hiring adequate personnell. Funds for renovations or development of additional space are also critical issues. Hospital care costs are significant due to the chronic nature of this disease.

## PREVENTION

We are hopeful that HIV-1 infection in Pediatrics can be prevented. This requires an emphasis on the family, particularly the maternal child unit. The epidemiology of HIV I in women and children is closely linked. Women are one of the most rapid growing groups recognized with AIDS. Many do not perceive themselves to be at risk. It is important that women be offered HIV testing, particularly in family planning clinics and prenatal clinics. They need to be aware of any risk to their infant. Also early recognition of women can facilitate family planning and allow themselves or their infants to enter into treatment protocols early as these become available.

## RECOMMENDATIONS

1. Congress should expand medicaid coverage for the full range of health care and social services needed by HIV-1 infected children.

2. Congress should suport funding of Pediatric AIDS health care demonstration projects in 1990.

3. Conress should support grants for outreach, confidential counseling and testing and Family planning services to women and adolescents at risk for HIV infection or already infected.

4. Congress should support research into 1) the natural history of HIV-1 infection in children, 2) mechanisms of perinatal transmission and the role of breastmilk, 3) developement of methods for early neonatal diagnosis, and 4) treatment of children with antiviral drugs through NIH supported clinical trials groups.

5. The Food and Drug Administration should review guidelines regarding testing of new antiviral agents in children.

6. Age appropriate HIV-1 education should be offered to all students at each level, beginning in kindergarten and continuing through grade 12.

7. Shelters and services for adolescents should be increased with special emphasis on runaway youth.

8. Increase the availability of drug treatment programs and related services for all, with a special emphasis on pregnant, drug dependent women.

Chairman **Miller**. Thank you. Dr. James.

## STATEMENT OF DEANNA JAMES, M.D., MEDICAL AND EXECUTIVE DIRECTOR, C.L. BRUMBECK COMMUNITY HEALTH CENTER, BELLE GLADE, FL

Dr. **James**. Good morning. I would like to bring you greetings from the H.R.S. Palm Beach County Public Health Unit in Belle Glade, Florida. I am Dr. Deanna James and I am the Director of the Belle Glade Public Health Unit. I have just completed my National Health Service Corps scholarship obligation and I have decided to stay on indefinitely, because I see a need for more work of myself and others if we are to help halt the spread of AIDS in our community.

Our clinic is Federally and State funded and we service about 8,000 single users per year, which is about 30,000 patient visits per year. We service the communities of Belle Glade, South Bay and Pahokee in Western Palm Beach County. The population of these three combined towns is 38,000. However, since 1981, we have had 304 AIDS cases reported from Western Palm Beach County, 98 percent of these cases are Black. Further, of the 3,130 AIDS cases that had been reported from Florida, 9.7 percent have been from this small area of Western Palm Beach County, population 38,000.

Even more striking is the fact that of 26,916 cases of AIDS in minorities in the United States, 1.1 percent have been from Western Palm Beach County. Currently we are following 405 HIV-infected persons, 100 are children and 305 are adults. We believe that HIV entered our community through intravenous drug use, but it has continued to spread because of multiplicity of sexual partners. This is supported by the 20 percent HIV infectivity rate we have in our sexually transmitted disease clinic, and by the 7 percent infectivity rate we have in our newborn and maternity clinic.

It is interesting that many of the women that know that they are HIV seropositive, do not want to have any form of birth control once they have delivered one child. They do not want tubal ligations, they do not want to use condoms and they have become sexually active in their pre-teen and teenage years. Unfortunately, we are seeing kids as young as six years old become sexually active and pre-school aged children mimicking their parents.

We also believe that substance abuse is contributing to the spread of AIDS in our community. A lot of young people are having what is called anonymous sex, they are having sex in order to earn money for crack cocaine and crank. Crank is the new drug of choice in our substance abuse population.

Also in our community we have seen a rise in tuberculosis, which is closely linked to the spread of AIDS in the community. A lot of young people, some with AIDS and some without, are contracting tuberculosis and spreading it throughout the community.

AIDS has continued to spread because of the cultural behavior in the Black community and in the Haitian community. As I said, 98 percent of our cases are American Blacks and Haitians. They do not want to use condoms, they feel that it is macho to have more than one partner and also that it is macho to spend money on prostitutes.

I would like to speak briefly about pediatric AIDS. As I said before, we are following 100 HIV seropositive children. Eight are currently school aged. We are following 16 children that have converted from HIV seropositive to seronegative and we think about approximately 20 percent of our HIV seropositive children at the present are converting from seropositive to seronegative. We are very concerned about what will happen to these children once their mothers die. We have foster care available, but it is limited for all children, not just for children who are HIV infected and we are concerned with who will be the caretaker for these children, once these mothers expire.

The services for AIDS patients in our clinic are provided by primarily National Health Service Corps physicians. We have myself and two others that are non Corps physicians. We have four internists, three pediatricians and two obstetrician gynecologists. Most of the patients that need services in our clinic are indigent. They are cleared by County Human Services, through an eligibility process that uses the Federal guidelines for poverty. Some are also eligible for Medicaid. Those that are ineligible, only have to pay a $3 fee if they are HIV seropositive or migrant.

Most of our patients are hospitalized at a very small hospital, Everglades Memorial Hospital in Pahokee, Florida. We are also straining their resources, because most of the private beds are taken up by our AIDS patients.

We work very closely with community organizations in prevention. We work with the C.D.C. funded HIV Prevention Center, and we work with the Comprehensive AIDS Program which is funded by Robert Wood Johnson Foundation and by HCFA. The Comprehensive AIDS Program provides home nursing services, counseling, and social services. The HIV Prevention Center provides health education and risk reduction activities. What we have been doing lately is getting together as a group and going out into the community to talk to children and others, in youth programs that we have been able to find during the summer, to try and make a coordinated organized effort in education in our area.

We have a lot of needs however. As I said before we do have health educators from the HIV Prevention Center, but even if we doubled our current staff, this would not be enough to reach all the contacts of all the people we currently have that are HIV infected. There is very little housing in this area for the homeless, and also very little for the homeless that are HIV infected.

We have one substance abuse program that is very small and it is for men. There is nothing for the many women that are substance abusers in the area. We need more funding for hospitalization, more funding for medication. In a few years, we probably will need more manpower, because the National Health Service Corps is drying up and there will not be any doctors to service the patients in this population unless we can provide some incentives for them to stay.

In summary, I would just like to say that I am very concerned with what is happening in Belle Glade. I do not want Belle Glade to happen in the rest of the country, even though as I travel around to different places, I see in the minority community that Black America is not responding to AIDS, that we are the last ones to get the information, we are not reading the pamphlets that Koop put out, and we are not listening to the news. So, what we are trying to do in Belle Glade is try and develop some culturally relevant materials so that we reach our target population. We use the type of music that the kids like, we do skits that they can relate to and things like that, but as I said, before this is going to be a very long slow process.

I do think that the community, the West Palm Beach County minority community is threatened with extinction and hopefully we can all work together and get something done.

Thank you.

[Prepared statement of Deanna James, M.D., follows:]

## PREPARED STATEMENT OF DEANNA R. JAMES, M.D., MEDICAL AND EXECUTIVE DIRECTOR, C.L. BRUMBACK COMMUNITY HEALTH CENTER, BELLE GLADE, FL

I would like to thank the House Select Committee for inviting me to discuss some of the unique problems of HIV infection in Western Palm Beach County. I am an Internist trained at Tufts University School of Medicine. I have completed a National Health Service Corps obligation at the HRS Palm Beach County Public Health Unit (Belle Glade), where I am currently the Director.

Our federally and state funded clinic services a population of 8,000 indigent migrant and seasonal farmworkers from Western Palm Beach County. This includes patients from Belle Glade, South Bay, and Pahokee. Even though these three areas have an off season population of only 38,000, 304 cases of AIDS have been reported to the CDC from Western Palm Beach County. Ninety-eight percent of these cases are in the black population. Of note, to date Florida has reported 3,130 cases of AIDS in blacks and the United States 26,916. This means that 9.7% of the cases of AIDS in blacks in Florida have been reported from Western Palm Beach County, an area with a poulation of only 38,000. Further, 1.1% of all 26,916 cases of AIDS in blacks in the United States have been from Western Palm Beach County.

We are currently caring for 405 active HIV seropositive patients in our clinic population. One hundred are children (newborn to age 17) and 300 are adults. We are hoping that a percentage of these HIV seropositive children will become seronegative.

We believe that HIV entered our population through intravenous drug use, but has continued to spread rapidly because of the multiplicity of sex partners in the black population. This is evident in the 19% infectivity rate in our STD clinic, and the approximately 7% infectivity rate in our newborn and maternity clinic populations. When informed of the risks to their unborn children, many HIV seropositive women do not want tubals. In fact, many women in our prenatal clinic have delivered more than one HIV seropositive infant. Many become sexually active in the preteen and teenage years.

Substance abusers are engaging in "anonymous sex" contributing to the spread of AIDS in this community. The drug of choice of our substance abusing population has switched from intravenous cocaine to crack and crank.

Coupled with the rise in AIDS has been a rise in Tuberculosis. We have expanded our clinic Tuberculosis services to treat the rising numbers of patients with Tuberculosis.

The AIDS epidemic in Western Palm Beach County is deeply entrenched in the cultural behavior of the infected population. Local Haitian American and Black American behaviors are greatly contributing to the spread of this epidemic. It is considered "macho", for example, for a heterosexual male to have multiple partners, not to use condoms, and to spend money on a prostitute.

### Pediatric AIDS

As previously stated, we currently have 100 HIV infected children eight of whom are school aged. Approximately 20% of our HIV seropositive newborns are converting to seronegative status. We are very concerned with caretakers for HIV seropositive children once their parents die. We are also cognizant of the fact that converters (seropositive to seronegative) will have to be monitored for several years.

### Services

Our clinic provides comprehensive care to HIV infected clients. Our physicians are all National Health Service Corps or former Corps physicians. Four (4) Internists, three (3) Pediatricians and two (2) Obstetrician Gynecologists are able to hospitalize these patients at Everglades Memorial Hospital (a non-profit hospital). HIV seropositive patients may be seen in our clinic for a nominal ($3.00 fee), if they are above county human service guidelines for eligibility or are ineligible for medicaid. The majority of patients, however, are eligible for medicaid or county clearance.

In conjunction with CDC and the HIV Prevention Center staff, the clinic staff provides health education and risk reduction case management for HIV infected clients in the community. The Comprehensive AIDS Program is a social service (HCFA and R. W. Johnson Foundation funded) agency that provides housing assistance, homemakers, and home nursing care for patients who have AIDS or ARC. These agencies work very closely with the Public Health Unit staff to provide coordinated medical care for HIV infected persons.

### Needs

This community needs additional health educators to provide follow-up and contact tracing of HIV infected clients. The staff of the aforementioned organizations must be increased if we are to halt the spread of this deadly epidemic.

Additional dollars are needed to provide housing for homeless HIV infected persons in our community. Substance abuse treatment centers must be established in our community. Health care dollars are needed for hospitalization, medication and manpower. With the diminuition of the National Health Service Corps, physician recruitment will be a major issue in Western Palm Beach County.

In summary, the AIDS epidemic threatens our predominantly black medically underserved population with extinction. Our clinic population consists largely of a group that tends to wait long periods of time before seeking medical attention. Education, beginning in early childhood is essential. Any efforts in education must be culturally sensitive to the values and behaviors of our community.

Thank you for your attention, and I am willing to supply any further information as necessary.

Chairman MILLER. Thank you. Ms. Garcia.

## STATEMENT OF ANA GARCIA, L.C.S.W., ASSOCIATE COORDINATOR, UNIVERSITY OF MIAMI PEDIATRIC AIDS DEMONSTRATION PROJECT, DEPARTMENT OF OBSTETRICS AND GYNECOLOGY, MIAMI, FL

Ms. GARCIA. Good morning, gentlemen, and thank you for letting me testify here this morning. My name is Ana Garcia and I am a Clinical Social Worker for the Department of Pediatrics at the University of Miami Medical Center here at Jackson. I am a social worker by career and training and a jack of all trades in terms of what I do here at the hospital.

The issues that I am highlighting this morning have been commented on briefly by the other panelists, but I would like to elaborate, and not to make it a very pessimistic testimony, I want to give some history here of some of the accomplishments we have had in our community.

I have been counseling families since 1983, together with Dr. Scott and our other immunologist. The issues have not changed, they have just increased in intensity or severity.

One of the positive outcomes of funding and listening to what the issues of children, are for our community, has been with the foster care program. We no longer have a boarder baby problem for HIV children, or children at risk, awaiting placement here at Jackson.

Children's Home Society has taken on the challenge of recruiting, counseling and assisting with the licensing, together with Florida Health and Rehabilitative Services here in Florida, providing 13 licensed foster homes, in which we have placed 25 children in the last almost two years. These are children who have been orphaned, abandoned or placed temporarily while their mothers have received drug addiction treatment, or their mothers have died of HIV infection and AIDS.

We have recommended through the years that HRS please offer placements with stipends to members of the children's extended or nuclear family in lieu of a foster care placement. We often have grandmothers, aunts and older siblings who are interested in caring for the child, but are unable to afford the high costs of raising them.

Now again, the rules for stipend incentives for families vary from county to county and that is part of the problem, there are very few services for families that are uniform across the State of Florida. Dade County does not provide this for an extended family member.

We now have Medicaid waiver in the State of Florida and I am happy about that, because it helps offset the costs of high medical care and it is also allowing some of our mothers to receive AZT treatment, if they qualify for Medicaid.

We have an incredible Dade County Public School program, where they have integrated HIV-infected children, mainstreamed them into the general population and have developed a task force, an advisory committee that addresses the needs of each individual child who has full-blown AIDS who may stay in the classroom, confidentially and anonymously and I would like to see this repeated throughout the other counties of the State.

Dade County Head Start Program has used this public school model to devise a plan to also integrate HIV-infected children into their Head Start programs. Day care with specialized needs identified for these children is nonexistent as yet and I am glad to see that Head Start is using this Dade County Public School model to develop their own. A few hours outside the home would benefit a child by providing external stimulation in a productive environment and allow the mother respite time to wash her hair, do her laundry or just go to the store, or maybe even sleep a couple of extra hours.

We have the development of the South Florida AIDS Network, that is multi-government funded, and they provide multi-discipline case management to patients affected by the spectrum of HIV disease in a comprehensive coordinated manner. And this is administered through the South Florida, the Jackson Memorial Public Health Trust.

All right, so these are our accomplishments. Now, this is where the request for funding comes. We have a very big problem with undocumented aliens in this very transient community of ours. Mostly originating from Caribbean islands and Latin America and it is seriously impacting their inability to, and ineligibility to receive social services. Their fears and anxieties of being identified to Immigration Services often leads to non-compliance and poor follow-through with referrals for HIV testing. Support services are limited to this population. However, their children are eligible for full services, because they are American born. Detention and possibly deportation are a real threat in their day-to-day existence here.

So, what I am saying is that the mothers, they are illegal, the children are born here, I can send the mother for Medicaid and possibly even welfare for her child, but that amount is so low because they are not counting her in. Some of the mothers who have one child will lose their AFDC allotment if the child receives Social Security Disability, it is all lumped into one check and the mother is dropped. And often times the mother is not aware that she is entitled to apply for Medicaid through some other programs and other mechanisms.

Shelters and housing. As Dr. James had stated, it is not just a problem in Palm Beach County, we have a problem here. For the homeless and displaced family with HIV infection, it is totally inadequate. the community would benefit by constructing dedicated facilities for displaced women and their children with nearby access to the Medical Center.

We saw a facility on Friday that they are selling for $500,000, it is a 23 room, one bedroom apartment, efficiency and combination and the owners want $100,000, perfect for infected women and their children. And right now, where are we going to find the money for such a center.

In recognizing that HIV infection has afflicted whole families, sometimes throughout three generations, it is our obligation to assure that the HIV-negative children and adolescents of those families receive the most comprehensive HIV prevention education and counseling. Not that they may not receive it now, but I think we should target them especially.

Often times these children are not aware of what disease has afflicted and claimed their whole family. It would be a doublefold tragedy if these children became infected by engaging in high-risk behavior as they grow into young adulthood.

We need a comprehensive education and outreach strategy to reach the male partners of HIV-infected women, as they are also grossly inadequate. Inter-generational macho attitudes interfere with men's acceptance and use of condoms and also affect their ability to cope with their female partners' positive status, leading to denial and refusal to be tested themselves. And what we have begun doing in the last two years, is asking these women, please name your baby's fathers and unfortunately what we are hearing is, it is the same dad to multiple women and multiple children. And these are still men who refuse to be tested themselves and to use some protective device.

The substance abuse problems in Dade County are reaching epidemic proportion. Increased funding to create and staff more drug treatment centers are required right now. Public residential and out-patient programs have limited spaces, insufficient to meet the needs of this community. We have counted approximately 5 in-patient public program centers and approximately 23 out-patient public centers and we could fill that ourselves with referrals from our Medical Center.

Crack babies are filling hospital beds as they await foster care placement, mother's lose custody and are often back on the streets or get pregnant while awaiting drug treatment. Narcotics Anonymous has yet to open support groups in the inner city areas, where the incidence of crack cocaine is highest.

Routine screening for HIV infection, while maintaining strict confidentiality, should be offered to all women of childbearing age. While respecting the same regard for confidentiality, voluntary partner notification should occur simultaneously, and funding for these two critical services are non-existent. If any attempts to impact on decreasing heterosexual and perinatal transmission are to be made, it would occur most efficiently through the provision of these two services.

And lastly, we would appreciate additional funds be allocated to AIDS service programs for hiring mental health supportive staff to assist the dedicated individuals who counsel and provide health care to HIV-infected persons. High mortality and case overload burnout the most invested care providers. As the incidence of AIDS cases increase, we must be assured that the pool of staff resources does not run dry. In most grants when you apply, the first thing that gets cut is mental health support staff, or the staff that do the work. And I said I wear many hats, that is one of the hats that I wear. So we cannot burn out our resources.

Thank you, gentlemen.

[Prepared statement of Ana Garcia follows:]

### Prepared Statement of Ana Garcia, L.C.S.W., Associate Coordinator, University of Miami, Pediatrics AIDS Demonstration Project, Department of Obstetrics and Gynecology, Miami, FL

Of over 90,000 reported cases of Acquired Immune Deficiency Syndrome (AIDS) in the United States, 8000 cases are in Florida. Miami has reported the third largest number of cases per million of the population.

In our city, HIV infection has touched the lives of all races, ethnic groups, social classes, men, women and children. There is an increasing incidence of HIV infection acquired through heterosexual transmission. In our community, it seems to predominately affect the impoverished, inner city Black and Hispanic population.

Last year, Human Resources Services Administration: Department of Maternal Child Health, released funds which were utilized to develop an intensive, comprehensive Case Management program for women and children with HIV infection. Through combined efforts, the University of Miami Departments of Obstetrics and Pediatrics has implemented this Case Management program in order to identify and address gaps in services to the families receiving Case Management services.

Eight years have elapsed since the first case of Pediatric HIV infection was identified at Jackson Memorial Medical Center. The community was not prepared to respond to the multiple problems and needs of this special population. Since 1981, we have come a long way in the availability and provision of medical and social services in Dade County. The following highlights the achievements and shortcomings of these services:

* Childrens Home Society, in cooperation with the State of Florida Health and Rehabilitative Services (HRS), and the South Florida AIDS Network at Jackson Memorial Hospital, have implemented a Foster Care program which has licensed thirteen foster homes and has placed twenty-five children, who have been orphaned, abandoned, or have been placed temporarily while their mothers receive drug addiction treatment. Although this is an admirable program, it has been recommended that HRS offer placement with 'stipends' to members of the child's extended or nuclear family in lieu of foster care placement. Often, grandmothers, aunts or older siblings are interested in caring for the child, but are unable to afford the costs of raising them.

* The State of Florida now accepts Medicaid waivers. This policy not only helps offset the high cost of medical care, but also assists in the payment of AZT for those who meet the eligibility criteria for treatment.

* In 1987, the Dade County Public School Board established an AIDS Task Force which addressed the issue of mainstreaming HIV

infected children into the general population. The program has successfully enrolled children into public school regardless of their HIV status, in a confidential manner, and has formed an Advisory Committee that meets as needed, to develop specialized care plans for the child with AIDS who is medically compromised.

* The Dade County Headstart Program has also taken the initiative to mainstream HIV infected children into their Day Care Centers and are using the Public School model to develop their plan. Day Care services for families dependent on welfare has been a seriously deficient resource for our population. A few hours outside the home would benefit the child (by providing external stimulation in a productive environment) and allow the mother much needed respite time for rest or other activities.

* Multi-governmental funding allowed for the development of the South Florida AIDS Network through the Public Health Trust at Jackson Memorial Hospital. South Florida AIDS Network provides multi-discipline Case Management to patients affected by the spectrum of HIV disease in a comprehensive/coordinated manner. Medical and social service referrals to unfunded residents of Dade County are directed through this Network of service providers.

Despite these great strides, the following critical issues need further funding and attention:

* Undocumented aliens originating from the Caribbean Islands and Latin America are the most seriously impacted regarding ineligibility for social services. Their fears and anxieties of being identified to Immigration Services often lends to non-compliance and poor follow-through with referrals for HIV testing. Support services are limited to this population. However their children are eligible for full services as they are American born. Detention and possibly deportation are a real threat in their day-to-day living experience.

* Shelters and housing for the homeless or displaced person/ families with HIV infection are inadequate. An HIV infected pregnant women with children cannot have her many needs met by the existing shelters. The community would benefit by constructing dedicated facilities for displaced women and their children with near-by access to the Medical Center.

* In recognizing that HIV infection has afflicted whole families, sometimes throughout three generations, it is society's obligation to assure that the HIV negative children and adolescents of those families receive the most comprehensive HIV prevention education and counseling. Often times these children are not aware of what disease has afflicted and claimed their whole family. It would be a double-fold tragedy if these children became infected by engaging in high-risk behavior, as they grow into young adulthood.

* Comprehensive education and outreach strategies to reach the male partners of HIV infected women are grossly inadequate. Inter-generational macho attitudes interfere with the men's

acceptance and use of condoms, and also affects their ability to cope with their female partners' positive status, leading to denial and refusal to be tested themselves.

* The substance abuse problems in Dade County are reaching epidemic proportion. Increased funding to create and staff more drug treatment centers are required now! Public residential and out-patient programs have limited spaces, insufficient to meet the needs of the community. Crack-babies are filling hospital beds as they await foster-care placement - mother's lose custody and are often back on the streets or get pregnant while awaiting drug treatment. Narcotics Anonymous has yet to open support groups in the inner city areas where the incidence of crack-cocaine is highest.

* Routine screening for HIV-infection (while maintaining strict confidentiality) should be offered to all women of childbearing age. While respecting the same regard for confidentiality, voluntary partner notification should occur simultaneously. Funding for these two critical services are non-existent. If any attempts to impact on decreasing heterosexual and perinatal transmission are to be made, it would occur most efficiently through the provision of these two services.

* Additional funds should be allocated to AIDS service programs for hiring mental health supportive staff to assist the dedicated individuals who counsel and provide health care to HIV infected persons. High mortality and case overload burn-out the

most invested care providers. As the incidence of AIDS cases increase, we must be assured that the pool of staff resources does not run dry.

Chairman MILLER. Thank you very much, all of you. Last year, the committee looked at the question of adolescents and AIDS and the exposure of the adolescent population to AIDS. We examined what we could expect in the future, working from the suggestion that adolescents may be the next big population of people in the country vulnerable to AIDS exposure.

Both of you have discussed this in one fashion or another, referring to either adolescents who were exposed at the time of birth, but who are now 13, 14, 15 years old and have AIDS, or adolescents who are being exposed apparently through IV drug use or sexual contact with an IV drug user. Is AIDS starting to close in on the adolescent population, especially in communities like Belle Glade? What do we know about this? Do we keep separate figures with respect to the adolescent population, or do we just count them along with the adults?

Dr. OXTOBY. I can speak for the figures; it is very important that adolescents be targeted as a unique group, because reaching them is quite different from reaching small children or reaching older adults. In terms of what we know about the extent of the problem, AIDS cases as I mentioned, is a particularly difficult way to look at adolescents because of the long incubation period——

Chairman MILLER. Right.

Dr. OXTOBY [continuing]. Between infection and AIDS. And, but however, there are children as young as 13 and 14 diagnosed with AIDS at that age, who have been infected through drug use or sexual contact. So we know that there are certain children being infected at very early ages. In terms of the extent of the epidemic in this group, there are several seroprevalence studies, including, well the, for instance Central Hospital Program, all of the seroprevalent studies include different age groups. So we are looking at adolescents as a separate age group, within all the studies of seroprevalence.

Chairman MILLER. Let me ask you, in your figures you talk about the number of individuals who are 20 to 24, or 25 to 29. If you work back in time, what do we know about those young people when they were 16, 17, and 18?

Dr. OXTOBY. Well, one of the ways is through the surveys of neonates, which is really evaluating childbearing women and that the age of the mother is looked at there. There are fewer women, fewer adolescents having children, but they are certainly present.

Chairman MILLER. Well, I guess I am worried that we are running into these people too late, when they are already infected, as opposed to going back into time and saying we should be looking at them when they are 13 through 18, if you will, to see what it is we can do in the prevention mode that keeps them from becoming a statistic when they are 20 to 29 years of age.

Dr. OXTOBY. Right.

Chairman MILLER. I am just wondering, is there some kind of surveillance, or are we trying to work up a means by which we can look at those adolescents in vulnerable populations to see what it is we can do on the prevention side of this issue?

Dr. OXTOBY. Right. There are specific studies of how common HIV is in certain very high risk populations of homeless, or adolescents in certain inner city communities. There is also a number, we know how adolescents get infected, it is not a mystery that it is drug use and sexual contact, so one of the ways we are trying to approach the problem is through knowledge, behavior, attitude surveys in adolescents, both in schools and out of schools and through interventions in that population, targeted at those risk behaviors, because we know that is how they are getting infected.

Chairman MILLER. Dr. Scott?

Dr. SCOTT. I think one of the other problems is that the adolescent age group is not a group that is routinely targeted for health care, like the young infant who comes to the doctor for immunizations and for routine school health checks. That is not true in the adolescent age group. So that the physicians and the clinics lose an opportunity to be able to impact on the adolescent. That is why it is very important, I think, that education in schools be targeted toward that group.

Chairman MILLER. Where are we in terms of what you think is important in this and the reality?

Dr. SCOTT. Well, I think that you know, if you look at how to reach the adolescents medically, perhaps health clinics related or associated with schools might be a way to target adolescents. I think that there are curricula being developed for that.

Chairman MILLER. Have we looked at populations where we have clinics in schools, with respect to AIDS? I mean, we have concentrated on it in terms of teenage pregnancy——

Dr. SCOTT. Right.

Chairman MILLER [continuing]. More or less, but we also know that a number of the clinics show that there are all kinds of other benefits with respect to the health of those young people. Have we looked at what impact these clinics may or may not be having with respect to AIDS and young people in schools? Is anybody measuring that, or are we just assuming that because they walk in the door they may be better? Are we upgrading the staffs to talk about AIDS in any of these programs, in any kind of pilot or experimental or demonstration projects?

Dr. OXTOBY. In terms of the school health education programs which are supported in all of the States and in several city departments of education, those are, as Gwen mentioned, curricula materials and other approaches to the youth in the schools that encompass a variety of different approaches, including the clinics. And within those programs we are now starting to evaluate what different approaches seem to be working, hopefully we will have some answers on that.

Chairman MILLER. Dr. Scott.

Dr. SCOTT. I would just say that you have really hit one of the crux of the problem in how to reach that population. I as an AIDS expert in infants and children know almost nothing about the adolescent population in Miami. I do not even know how many school health associated clinics that we have. But I think that in thinking about the problem, you know, that certainly would be an area where one could impact directly on adolescents.

The other problem I would mention, is that in dealing with adolescents, sometimes one has the problem of permission and who gives permission, and who do you share the knowledge with, because adolescents in a sense may give permission for themselves, but on the other hand, one still needs parental permission to do certain other types of medical care. So sometimes, at least in thinking about medical/legal types of things and ethical types of issues, that is another consideration that people think about when they are dealing with adolescents and in some ways may actually obstruct testing and counseling in this age group.

Chairman **Miller**. Dr. James, where would young adolescents go to get information in Belle Glade?

Dr. **James**. In Belle Glade they would get it from our staff, the physicians on our staff.

Chairman **Miller**. What, are you school based?

Dr. **James**. No, we are not school based.

Chairman **Miller**. You are not school based, right?

Dr. **James**. No, we are a public health clinic, but most of the adolescents in the public school system come to us for their care. We have not started a separate adolescents clinic, but we will be. We do have HIV-infected adolescents, and we have pregnant HIV-infected adolescents. We are doing health education in the schools, as I said, with the Comprehensive AIDS Program, with the HIV Prevention Center. We just did one last week as a matter of fact. We are going to try and do it during the school year as well. I did some myself last year. The school board has allowed a number of people, to come in and do AIDS prevention education. They also teach AIDS prevention education in schools now.

Chairman **Miller**. You mentioned in your testimony, and I visited Belle Glade some years ago, touring much of the housing in the community and traveling throughout the community in general. If it as I remember it, you are quite right, it would seem to me that you have got a community that converges on extinction. I mean, if you keep up these combinations of behaviors within this population and given the closed nature of the community to some extent——

Dr. **James**. Right.

Chairman **Miller** [continuing]. It is not a far fetched notion that this is essentially what you are talking about. Between drug use, sexual activity and AIDS, this community can wipe itself out.

Dr. **James**. That is correct. I basically think that we cannot address the AIDS epidemic without addressing the substance abuse in the community. This AIDS was basically the last thing the community needed. There is inadequate housing.

Chairman **Miller**. Inadequate, you are being very polite.

Dr. **James**. The young people in the community already have low self esteem. To try and go in and build them up and try and get them involved in things other than drug use and abnormal social behaviors, will be difficult. One of the things that they always say is there is nothing for them to do in Belle Glade. They have no recreational center there for the minorities in the community and there are no organized social activities so that the young people tend to get into sexual activities.

Chairman **Miller**. Do you still have a large influx of can cutters, seasonal workers that come?

Dr. **James**. Yes, we do. They do not come to our clinic for services usually.

Chairman **Miller**. But they are in the community?

Dr. **James**. They are in the community. There have been some that have been HIV infected. We get referrals once they become infected.

Chairman **Miller**. Do the employers provide any kind of health care?

Dr. **James**. Yes.

Chairman **Miller**. Surveillance?

Dr. **James**. Oh, surveillance, no the employers have asked us to come and test for HIV infection, but we have not been there yet. I think the HIV Prevention Center is planning to go. There are some infected cane cutters.

Chairman **Miller**. Do they provide any kind of financial support for any clinic other than yours in the area?

Dr. **James**. They have private health insurance for their employees, and so they can go to the private physicians in the community. The problem is that the private physicians are not testing for HIV. The clinic basically and the HIV Prevention Center are the only organizations to actively test for HIV infection. A lot of them do not test for HIV infection. And it is when the patient is critically ill in the hospital and there is a suggestion from a public health doctor that the patient might require HIV testing that he is tested.

Chairman **Miller**. What are we experiencing in terms of multiple births to HIV infected individuals? Where are we now? We have a number of years under our belt here, what are we——

Dr. **James**. We have approximately 12 women now; (A couple of months ago it was 10), that have had multiple births of HIV-infected children. Some of them have had at least three children that are HIV infected.

Chairman **Miller**. Some of those children have died?

Dr. **James**. Yes, some of them have died. The women feel that this gives them new life to continue on, and they say that "yes, I am healthy, I can still reproduce," so they continue to have children, even though that they have lost one child. They also say "well maybe this one will live, and look at me, I can still have a child so I must be all right".

Ms. **Garcia**. I think it also often goes beyond that. I mean you look at all the reasons why the women choose to have children, one is to replace the child that is dying. There is often times, our experience has been that the woman has not shared her HIV status with her partner and he may want his own family, he finds out that the baby is infected and that the woman is infected and he splits. And of course this is an economic measure for her possibly, so she finds another caretaker. And again, you know, issues of self esteem, it makes her feel worthy and womanly to be able to have a child, and we regard adolescents who often have impaired judgment and limited insight at the time, this is not restricted to the older woman, it also occurs within the adolescent population. And often times even the male partners turn to prostitution for crack.

Chairman **Miller**. Well, you know, we have talked to some people in a hearing and a lot of national attention has been given to the notion of grandmothers taking care of crack babies, and AIDS babies in San Francisco and elsewhere. In a community like Belle Glade, you will run out of grandmothers real quick.

Dr. **James**. That is true and the problem in Belle Glade is that some grandmothers are infected too.

Chairman **Miller**. That is what I am saying, the generations are so close, there has been a collapsing——

Dr. **James**. Right.

Chairman **Miller** [continuing]. Of the time frame here.

Dr. **James**. The daughter may be 12 and then her grandmother may be 24 and her mother may be 36.

Chairman **Miller**. All infected?

Dr. **James**. Right, right. We have families with nine people infected. It is very traumatic.

Dr. **Scott**. I would just also add that the majority of these women that deliver infected children are not sick. So that many of them have a lot of difficulty with the concept that they carry a virus that they can transmit to their child, that produces a deadly disease in their child when they themselves are clinically well.

Chairman **Miller**. All right and where are we screwing up in terms of being able to communicate with these individuals in terms of materials, or in terms of approach?

Dr. **Scott**. It is a very difficult.

Chairman **Miller**. I mean it seems very haphazard. This is not, you know, in all the communities—I mean Belle Glade is somewhat unique. In terms of Dade County and South Florida, the whole problem is trying to communicate with a population that in many instances is very young, lacks education, and lacks sophistication. Yet I do not get the sense that we are promoting the kinds of contact and communications skills necessary to talk to these people to see if there is any chance of changing their behavior.

Dr. **Scott**. I think that what Dr. James is describing in Belle Glade has gone on in Miami for many years. And you cannot imagine the frustration of people who have counseled patients over and over and over again about status and about risk of having infected children and risk of transmission of the virus to others through sexual contact.

Chairman **Miller**. So you are also being ignored?

Dr. **Scott**. This must be done in an age appropriate and culturally appropriate way and we have hired many workers, you know, from the same ethnic groups to help and assist with counseling. But it becomes sometimes more fundamental than that, sometimes it is a religious belief, sometimes it is an incapability of actually understanding how they can have a virus and can transmit it. Sometimes it is denial, denial is a very wonderful method of protecting oneself. And it just points out, you know, each individual is very different in terms of counseling. And that counseling needs to be ongoing over time and you cannot just counsel them once and feel that you have done a good job.

Chairman **Miller**. Let me ask you something, then I want to turn over to other members of the committee. In the issue of denial, you have individuals obviously that, as you have explained, would deny AIDS for a number of different reasons. But also you counsel them for an hour, a couple of hours or whatever amount of time you have contact with them. You are then returning that individual to a community that may on a community basis be denying this. Is that happening?

Dr. **Scott**. I think to some extent that is true. I think that in the past, particular educational information was not getting out to specific minority communities about the disease. And I think that you know, the whole community needs to have an awareness, but I still think that there is fear and hysteria and concern out there in the specific communities about this disease. And so I think that it really is going to require a very targeted, very intense effort to educate. I think that just attempting to educate in the use of condoms has been a challenge in many of the groups that we serve.

Chairman **Miller**. I have some additional questions, but I think what I will do is, if I might, submit some of these to you in writing and see if we can get a response from you, or you can provide us the materials. Congressman Lehman.

Mr. **Lehman**. Thank you, Mr. Chairman. I just listened to all these overwhelming problems and I have to call to mind in the recent weeks the Congress has passed a defense bill that provides at $500 million a copy for 13 stealth bombers and plan for 50 altogether. It seems to me that we are putting money up for a stealth bomber, when we have a stealth bomb right here in our own community, which is a lot more dangerous. Something is deadly wrong with our sense of priorities in this country and I would like to see that changed.

But the problem as I see it, and you talked about the mothers, the group of mothers, of women that carry the HIV at this time that if they know they have it, apparently they have this desire to, have children to carry on their life. Someone said their own immortality sort of. If they do not know, if they deny it, if they go on and have children anyway, if either the child suffers, they are placed often in intensive care, or if the child does survive, many of them are ill and do suffer. If the child eventually dies before adolescence, that is one end, if the child somehow or other, as some do, survives into adolescence and becomes a sex partner herself or himself, then they become an extension of the original mother who passed on the virus to the child. Either they die or they become carriers, it is a no win deal, am I correct?

Have you found that most of these mothers come to the hospital in the latter part of their pregnancies? I assume very few come early in the pregnancy?

Ms. **Garcia**. No, we do see some early in the prenatal, in their prenatal care. Not as many as we would like to.

Mr. **Lehman**. Well, then I ask you the $64,000 question. If you had a mother come to you in the early part of her pregnancy that was HIV infected, would you advise this mother to have an abortion?

Ms. **Garcia**. No, sir; I would ask the mother what does she want, and I would help her explore her alternatives and if abortion is her choice, then it is my responsibility to help her through that process. But they bring it up.

Mr. **Lehman**. Would any of the other members of the panel counsel the mother to have an abortion? Is that a fair question?

Dr. **Scott**. A federally funded? No.

Mr. **Lehman**. I mean, these are hard questions we have to look at.

**Dr. James.** Right. We counsel the woman about the importance of prenatal care. We also give them the option of tubal ligation, but as I said before, none of them want tubal ligation. All of them want the babies. They see this as an attachment to a man, they see it as money in the future in the form of a check that will come monthly, and they see it as life. But we, you know, we offer them options, although we cannot perform abortions.

**Mr. Lehman.** I have had two answers that say they would not accept counsel, but would accept the mother's desire.

**Dr. Scott.** Well, I would just like to say that I think that perhaps one of the reasons that abortion is not recommended is that we are still in the process of determining the rate of perinatal transmission.

**Mr. Lehman.** According to Dr. Oxtoby, it runs between 35 and 50 percent is that right?

**Dr. Oxtoby.** Most likely around one-third, the range has been 25 to 50.

**Mr. Lehman.** Twenty-five to fifty percent, it is pretty high.

**Dr. Oxtoby.** It has been dramatic.

**Mr. Lehman.** That is a pretty high crap shoot.

**Dr. Scott.** And those figures, the 35 percent figures have just really been coming into literature very recently. So that this disease at this point in time is treated in general like other, like other diseases in that the mother is counseled with regards to the risk and it becomes a decision on the part between the mother and the physician, with regards to abortion.

**Mr. Lehman.** But is it not also a social problem as well now, because you have given birth to these children that are going to be suffering and you have these children that—I am not recommending it, I am just trying to assess the problem. With the children who go through their childhood as suffering people and eventually become carriers themselves, is that not a social problem and not just a problem between the mother and the physician?

**Dr. Scott.** It is true, but it is handled like most other types of congenital——

**Mr. Lehman.** Should it be?

**Dr. Scott** [continuing]. Problems, and——

**Mr. Lehman.** Should it be? Do not answer that. Who would like to answer that question?

**Dr. Scott.** The other thing I think though, that there would be some women that might be willing to accept abortion, but in general, they do not have the funds for abortion. We have had some women who have gotten abortions out in the community where they can pay much less, but I think that one of the other problems associated with accepting abortion, is that there does have to be money up front for that abortion and they do not have that kind of money.

**Mr. Lehman.** Should it be funded by the Government at some level, if the woman wanted an abortion?

**Ms. Garcia.** Well, I do not know, in light of where the abortion ruling is going, State by State, no I am very concerned. Medicaid does not pay for terminations right now, they are anywhere from $135 to $235 and if you have them here at our Medical Center, you will eventually be responsible for the payment of this debt. Should it be federally funded, I would say as a social worker, yes, because the women have enough to deal with in issues of poverty without having to think about how am I going to terminate if I do not have any food to eat.

Mr. **Lehman**. Dr. Oxtoby, you have any comments? You have been very quiet.

Dr. **Oxtoby**. I think what we are discussing is a real important issue. I think it is just one very small part of the whole issue of contraception and family planning. Many of the women do present very late or have no prenatal care at all. And the other thing is although people have discussed women wanting to have children, they are also quite a number of women out there who really do not have access to family planning services early on, adolescents and young adults. So I think bringing some of the programs are trying to bring family planning into settings such as drug treatment clinics, SCD clinics, and also bring HIV counseling into family planning clinics. And I think that those will be important prevention efforts.

Mr. **Lehman**. We were talking about AIDS mothers and family planning. It is a whole different ball game and that is the problem. This is not ordinary family planning where the mother and father are getting along well, or about their financial problems, this is something that society has to deal with. Let me ask you one more question. I am just trying to find answers to these problems and solutions to the social impact of them, if there is any. Would you like to see a law that provided sterilization of mothers with HIV, or even mandated mother sterilization, would that be a solution? I am just throwing these things out. These are not the questions we want to hear, but these are questions that people think about.

Dr. **Scott**. I guess I would start out by saying I have difficulty when things are mandated. But I think that one thing that we are looking at is treatment of pregnant women with anti viral drugs in an attempt to prevent transmission to the infant and that is something very new that we will be starting in one or two centers to look at the pharmokinetics of drugs, so that there may be in the future some ways to prevent transmission of disease.

Mr. **Lehman**. From the best information I can get, the real cure for HIV is still decades away. I mean, there may be a breakthrough, but right now we are not looking at one.

Dr. **Scott**. Prevention is very important.

Mr. **Lehman**. Does anybody else have an opinion on whether you either recommend sterilization, or whether you think that is a solution, or whether it should even be mandated? Anybody want to voice an opinion on that? Thank you very much.

Dr. **James**. I was just going to say I think such a law might be very discriminatory.

Mr. **Lehman**. Well, I am not trying to change the law on sterilization. I am just trying to find a solution, and I think it would be a solution. On the other hand, one third of the babies that are from infected mothers, the ones that have infections, they either suffer and die or grow to maturity and are as I said a stealth bomb in our society. We do not have easy solutions. We have a win/lose situation at this time in dealing with this problem. I do not see a positive answer, except a compassionate answer to make these people, these children as comfortable as possible and to care for them as best as possible.

Ms. Garcia. Congressman Lehman, if we are ever going to consider any kind of mandatory process where a woman should have to come out——

Mr. Lehman. I am in the same——

Ms. Garcia. You have the same sort of respect somehow.

Mr. Lehman. I am for the same woman's rights as you are.

Ms. Garcia. All right.

Chairman Miller. We can always count on you Bill. Mr. Durbin.

Mr. Durbin. Thank you, Mr. Chairman. Dr. Scott, I want to understand a couple of things about this and it has been a very illuminating morning for me in terms of testimony. But it is my understanding from what Dr. Oxtoby and you have said, that if the mother is infected with HIV, the likelihood of the child carrying that disease is one third to 50 percent roughly, that is what the statistics indicate?

Dr. Scott. Roughly.

Mr. Durbin. All right. Is there any value to your knowledge, of the mother's HIV infection early in the mother's pregnancy?

Dr. Scott. I think that if our obstetrician were here, she would say yes, because she would follow that mother more frequently. We have had some mothers during pregnancy who have developed opportunistic infections particular a pneumosystic cranial pneumonitis and she would want to follow the growth and the development of the infant very carefully.

Mr. Durbin. But at this moment, it does not afford you any unique or additional opportunity to avoid the onset of the infection, the knowledge of the pregnancy?

Dr. Scott. To avoid the onset of infection in the child or the in——

Mr. Durbin. Yes——

Dr. Scott [continuing]. Or in the——

Mr. Durbin [continuing]. In the child.

Dr. Scott. Okay, yes, because at this point we do not understand what factors allow transmission. In the very near future, and near future may be six months within the next year, it might be possible that pregnant women will be afforded treatment under protocol, with anti-viral drugs in an attempt to see whether that modality might prevent transmission.

Mr. Durbin. Could one of the agencies which I fund, through my work on funding through my appropriations committee assignment is the Food and Drug Administration and of course it is in the center of controversy on this whole issue. Do you feel that there is adequate attention being given by that agency to this whole question of pediatric AIDS?

Dr. Scott. I think that the two issues need to be resolved with regards to the FDA. One is the beginning of trials very early in children, almost concomitantly with adults, particularly in phase one trials, because in some trials, particular the AZT, the trials in children were started very late. And therefore, we know much less about AZT in children than we do in adults. So that we need to start new drugs concomitantly with the starting of those drugs in adults, as soon as a few adults have been treated.

The other issue is the issue of women and pregnant women and being able to gather information quickly about potential trangenicity of drugs and effect in pregnancy, looking usually at animal studies. And then perhaps as more is know about the drug, to be able to look at them in pregnant women. But again, that would usually be after it had been studied to a greater extent in non-pregnant males and females.

Mr. DURBIN. What percentage of the mothers of HIV-infected children are IV drug users themselves?

Dr. SCOTT. Again, if you look nationally, about 50 percent, is that right?

Dr. OXTOBY. Of the mothers of drug users.

Dr. SCOTT. IV drug abuse.

Dr. OXTOBY. About 55 percent yes.

Dr. SCOTT. Fifty-five. In Florida, it is less and in our own population we see about 55 to 65 percent transmission by presumed heterosexual spread. But I can tell you that the problem of drug abuse in the women, we are seeing a growing population of children, because of drug abuse in the women now in Florida.

Mr. DURBIN. I would like to, having asked those factual questions, go to some of the policy considerations, which we addressed this morning. Let me say at the outset, Dr. James, that many of us and I think all of us on this panel have been fighting a battle for at least the last eight or nine years to keep the National Health Service Corps in business. There has been a proposal by President Reagan year in and year out to eliminate this program. And most of us, by instinct, have been thinking that this is the wrong thing to do. Your presence here today and your testimony convinces me thank goodness that we were right and that we have got to keep this valuable program in place, so dedicated people like yourself can continue to address public health needs in America. Thank you for coming and presenting what is critical to a politician's success in Washington, anecdotal evidence. I now have a story that I can tell all across into my District and in the halls of Congress about how important this program is.

Let me try to move to a couple of policy questions and ask for your response. First, Ms. Garcia, you told the story, a lot of aspects to the story and the close of the testimony with Congressman Lehman, you referred to it again. I recall your testimony about the, for lack of a better term, the serial infector, this father out there, HIV infected, who proceeds to impregnate young women and pass along this infection time and time again. Do I take it that there is nothing that you know, at the moment, that can be done to stop him either State or Federal law, whatever?

Ms. GARCIA. From my point of view, short of murder, no there is nothing that I can do right now. In our case management program, through the PDA's demonstration project, we have hired three male social workers. I obviously can see from a female advantage that a man is not going to listen to my counseling about what he should do with his partner. So we felt that maybe man to man ethnic group to ethnic group, culture to culture, they would understand each other a little better and it is going to be a long process. But I think the focus will always be one to one education, or maybe even some group work with the men. It is all macho, it does not matter what culture or what ethnicity you come from, it is a way of being that is handed down, generation to generation and now is when we can impact on changing macho attitudes. You can be masculine, without being——

Mr. **Durbin**. Irresponsible.

Ms. **Garcia**. Yes, thank you, I was going to say something else, but, that is okay.

Chairman **Miller**. Submit it in writing later.

Mr. **Durbin**. The questions which we have asked this morning and the one I just posed to you raises some interesting analogies. If that person, if that man whoever he is were guilty of causing young children to become addicted to drugs or in abusing children, physically or sexually, we have all sorts of responses. They may be inadequate, but we at least have said you have crossed the line, society will not allow you to continue to do this. And yet, we know by the activities by this serial infector he continues to wreak havoc, not only on his mate in this situation, but his progeny as well, time and time and time again. And we sit back with our arms folded, saying is it not difficult to accept, there is just nothing we can do about this, under the law there is nothing we can do, except maybe try to counsel him to become more reasonable. Therein lies our frustration. I think that it leads to the line of questioning from Congressman Lehman earlier.

But let me ask you, if others of you have comments on this please join in, but let me ask you a practical question. If we required young children in America to be examined and inoculated to attend school and then virtually every jurisdiction across our nation, no one questions this except for some religious belief that might come into concern, but that is a very, very minor percentage, why do we not require a screening of adolescents when they reach the age where they could become pregnant, to determine whether or not they are either infected or drug addicted? Does anyone see any problem with that? I am not going as far as my colleague, Mr. Lehman before, but what if we were to try to establish early in a person's adolescence, whether or not they have already demonstrated some evidence of drug addiction or even HIV infection.

Ms. **Garcia**. Well, from a social service standpoint, I know that if you were to create and implement such a voluntary screening or testing program——

Mr. **Durbin**. Not voluntary, mandatory.

Ms. **Garcia**. Mandatory.

Mr. **Durbin**. It is not voluntary for kindergartners.

Ms. **Garcia**. Well, again I would have to just go along with what Dr. Scott says about having problems with anything that is mandatory. I think with some adolescents who may be responsible, but you know, there may not be too many of them. It is still awkward in a voluntary setting, you have to have comparable social services to go along with that, counselors to handle the pre- and the post-test counseling. If the adolescent is becoming symptomatic a system through which you can refer that person for care. We have adolescent medicine clinics, you know, they are kind of like caught in the middle. Adolescent medicine only does, you know, can only do so much, but they are too old for pediatrics and too young for young adulthood.

I think in some of the detention centers around the country, testing is offered, pre and post test counseling goes hand in hand and then what happens with that individual when they are released from detention. There is no facility for that individual to go, based on a positive status. So again, you know, if you ever consider that, you have to have the other services——

Mr. DURBIN. I do not take anything away from your testimony, you are right, the support services have to be there once you have the information. What good is it if you do not do something with it? Dr. Scott, back to your earlier testimony, if knowledge of the infection earlier in pregnancy assists you as a doctor in treating the mother and the child in utero, what do you think of the proposal that we have some mandatory screening to determine through, either through the school or through those who present themselves for Title X counseling, or whatever, to determine whether or not we have a mother or potential mother at risk?

Dr. SCOTT. Right now I think that with any kind of testing, must go confidentiality, because one of the great concerns about people who are positive is who finds out that test result and what is done with that.

Mr. DURBIN. I assume confidentiality. This is not for publication, it is between that child, perhaps their parents if they have to be involved in the decision as you said earlier, and the doctor or counselor.

Dr. SCOTT. Assuming that you could assure that confidentiality, because I think that is still a problem and people are discriminated against because of HIV positivity. I think that first of all you cannot do it on just a one time basis. I would not know what age to choose first of all, because there may be 13 year olds who are sexually active and abusing drugs, but there are other 13 year olds who at 15 may begin to do that. So I would not know what age to choose as a time to do testing.

And secondly, if I found that an individual were HIV positive, I would feel that since they are an adolescent that that person would require very intensive ongoing follow-up and counseling. And that patient should have access to any kind of treatment programs. That patient should have access to ongoing counseling with regard to pregnancy, sexual activity, drug abuse, what have you. So I think that along with that kind of a testing, would need to go a very comprehensive program that would be devised for such individuals.

Mr. DURBIN. Thank you very much. You are a great panel and you have really helped educate me and I am sure my colleagues. Thank you, Mr. Chairman.

Chairman MILLER. If I might, just in closing with this panel, I want to certainly thank you for your help and ask if you might respond to some written questions that we would submit to you at the close of this.

I think what you are seeing here is a very real concern about our ability to withstand this onslaught of AIDS and of course the related problem of cocaine babies. And I think that to date, as long as the Select Committee has been following these two issues, we have not found any institution or society that has withstood the onslaught of this population.

It is in fact overwhelmed all of the hospitals, all of the school systems, foster care systems, and adoption systems that are starting to encounter it. It does not really matter that we have not had the ability. And there is a very, very real concern on how we provide some kind of circuit breaker in these communities to the self-destructive behavior and obviously to the results.

The questions of testing, of sterilization, of abortion, I will have to tell you are being discussed more and more among policy makers as the frustration level rises. I expect to the same extent to see legalization of drugs being discussed when people do not feel that they are making headway.

You know, I am told that we test now in the armed forces, mandatory testing. We find, I think, about a 2 percent rate, both for drugs and for HIV. We test in the Job Corps, and very interestingly enough, when we find something, we just throw them out. We do not put them into any counseling, we do not put them into any treatment, we do not put them into any prevention programs and we simply cut them loose. So that may be indicative of where we are in terms of our discussion about how we want to change behavior.

And, while I see these very drastic suggestions creep into the discussion, privately if not publicly among policy makers, I am still terribly concerned that I have not yet in any part of the country met any institution that has had sufficient resources to deal with this problem on what they believe is a first class basis. Everybody is sort of knitting together approaches.

We have contact with millions of sexually active individuals in Title X programs, millions of sexually active individuals in the WIC programs, and yet somehow we are not able to raise the skills and go after people so that they can start dealing with the problems of drug use, or of HIV, within just those populations. Because somehow there is not enough money at the local level. The Congress—and we have got to take the lead here—is not willing yet to look at this in a comprehensive fashion. We are long on demonstrations and pilot projects, but nothing in a comprehensive nature. It is ridiculous to go out and suggest that we are going to subject women to sterilization and/or men to sterilization at a time when we have not even scratched the surface in seeing whether we are willing to work with these populations, as difficult as they are. As you all know this is a very, very difficult population, especially when you tie it in with drug use so that your chances of dealing with it are dramatically reduced.

But, if I am hearing discussions in the Congress correctly, there is a great deal of frustration, as I am sure you have experienced in the field for a number of years. And I do not know where we go, that is part of what this hearing is about—the development of a response to this population.

So, thank you very much for your help and your time this morning.

Our next panel will be made up of Mr. Philip Plummer who is the Administrator of the South Florida AIDS Network; Manuel Laureano-Vega, Dr. Manuel Laureano-Vega, who is the Executive Director, League Against AIDS from Miami, Florida, who will be accompanied by Mireille Tribie, Dr. Mireille Tribie, who is the Assistant Director, League Against AIDS; and Rev. Dr. Roger P. Miller, who is the Chaplain in AIDS Ministry and Chairman of the Miami AIDS Interfaith Network from here in Miami.

Welcome to the committee. And again your prepared statements will be placed in the record in their entirety. And the extent to which you can summarize, or you feel you want to comment on something that was said by a previous panel or member of the committee, please feel free to do so. We would only ask you to try to keep your testimony as short as possible, because as you can see it stimulates a number of questions here from the members of the committee.

Mr. Plummer, we will start with you.

### STATEMENT OF PHILIP PLUMMER, ADMINISTRATOR, SOUTH FLORIDA AIDS NETWORK, JACKSON MEMORIAL HOSPITAL, MIAMI, FL

Mr. PLUMMER. Thank you very much for the opportunity to present today. I see the problem with AIDS as a really a problem with HIV infection and has been pointed out in the panel this morning, in order to fully appreciate the impact of AIDS in children, one must understand that for every HIV-infected child that we identify, we are also identifying an HIV-infected mother.

Chairman MILLER. Excuse me if I might. If we could just ask the people who are going to engage in conversations, if you could do it outside, so that we have an opportunity to hear the witnesses. Go ahead, Mr. Plummer.

Mr. PLUMMER. Approximately 98 percent of the children with HIV infection currently being cared for at Jackson Memorial Hospital, have been infected through perinatal transmission.

Within our Pediatrics AIDS Demonstration Project, the following data has been collected on a sample of 100 HIV-positive mothers. The racial and ethnic background, 84 percent are Black, of which 27 percent are of Haitian origin; 14 percent are Hispanic; and, 2 percent are White.

The age ranges is between 13 and 46; 5 percent being under 19 years of age; 22 percent being between the age of 19 and 24; and, 73 percent being between the ages of 25 and 46.

The marital status of sample; 77 percent are single; 19 percent are married; 3 percent are divorced; and, 1 percent are widowed. Clearly, 81 percent of these women in the sample group are of single family homes.

Again in this sample, 18 percent of the mothers enrolled admit to substance abuse, with the drug of choice being crack, intravenous drugs and/or alcohol, compounding the problem of HIV infection. Two point one percent of the babies delivered at Jackson Memorial Hospital, approximately 14,000 to 15,000 deliveries, are of HIV-infected mothers.

Therefore, in talking about the costs of caring for HIV-infected children we must look ahead of the birth of this child and consider the cost of providing testing and counseling for HIV-infected mothers. Now the question was asked whether the testing and counseling of HIV-infected mothers, or the pregnant women, should be mandatory. I do not think it should be mandatory, but I do think we need to put the dollars into offering this service.

Just looking at providing testing and counseling for the 14,000 deliveries at Jackson Memorial Hospital, we are looking at approximately $1 million to provide this service. This is an average of $71.42 per pregnant woman.

What does this get us on the other hand? For those women who are not infected, with a good testing and counseling program, we are hopefully providing those women with information on not becoming infected. So we are not just dismissing them, saying that you are not infected, bye bye now, we are providing counseling in terms of how they can prevent future infection.

With the 2.1 percent of the population of pregnant women who are infected, the approximate 300 mothers annually, we are providing early intervention which Dr. Scott indicated could potentially help us in the early identification and treatment of the child.

The second cost involved in the care of HIV infection also occurs prior to the birth of the child. Providing the identified HIV infected expectant mother with intensive prenatal care. We have got to consider the impact of HIV infection, not only on her, but also on her unborn child.

Providing identified HIV-infected expectant mothers who are substance abusers with a rehabilitation program, or at a minimum a safe space where they can remain drug free through the remainder of their pregnancy. Currently there are no substance abuse treatment programs that will accept a pregnant HIV-infected woman. This is something we need to develop. I feel that we can develop a program like this at the cost of approximately $390,000, with our current resources. Obviously, as this group increases, the cost will increase.

The third pre-birth cost is that of providing a nutritious, balanced diet for all identified HIV-infected expectant mothers. I think that without a doubt we can look at the impact of nutrition on the progression of HIV infection, not only in expectant mothers, but also in their unborn children.

Once a child is born to a HIV-infected mother, there is a necessity for providing medical follow-up for that child to determine the child's HIV status. As was mentioned by the physicians this morning, approximately a third of the children born of HIV-infected mothers will be HIV infected themselves.

However, until we determine that, within a period of between 15 months and two years of age, probably closer to 15 months, these children we must assume are HIV infected. Everyday colds, flus, ear aches, et cetera that these children experience must receive prompt medical attention.

The cost of actually caring for an HIV-infected child is outlined in the attachments. You can see from the attachment that the numbers of children needing hospitalization, the numbers of children needing out-patient care, the numbers of children needing foster care, and the number of children needing home health care has increased over time, this is due to the increased numbers of children we are dealing with.

For instances, in 1987, we hospitalized here at Jackson Memorial Hospital, 45 children. In 1988, that rose to 65 children and in 1989, we are talking about a six-month period of time, we have already hospitalized 48 children.

The daily cost of caring for these children has also gone up. This is primarily due to the very expensive antibiotic medications and other medications that are needed to care for these children.

With early intervention and prevention, I think that we can start to decrease some of these costs. As you can see, our average length of stay for these children has decreased from 1988 to 1989. An important aspect of care for HIV-infected children is out-patient care. The numbers of children that we are providing services to has obviously increased. We are beginning to see that we can decrease the costs, the average cost of caring for a child on in an outpatient clinic. This is really through early intervention and detection and early involvement with these children.

Foster care, is a growing component for caring for HIV-infected children. In 1987, we had nine children in foster care; in 1988, you can see that rose to 40 children in foster care; and, in 1989, again half of a year, we have already had 29 children in foster care. This will probably increase to almost double by the end of this current year.

The cost of caring for children in foster care has increased, but that is primarily due to the fact that in foster care we are providing for a larger number of HIV-symptomatic children and therefore the cost is increasing.

Again, when you consider that the 98 percent of the children that we are caring for have infected mothers, mothers who are getting progressively sicker, the need for foster care—and mothers who are also dying—the need for foster care is going to increase significantly for us over the next couple of years.

We are also providing intensive home health services to a larger and larger number of children. You can see from 1988 to 1989, (in six months of 1989), we have provided home health care for as many children as we provided for in the total year of 1988.

The final cost for care of HIV-infected children must be related to the cost of providing services to the caretaker, not only the HIV-infected parent who is a caretaker, but also the nurses that are going out to see these children in the home, the foster parents that are taking care of these children. In foster care we have already had three deaths of children. Just to provide the mental health services to this group of people who are taking care of HIV-infected clients is very very important to us.

The mental health services to the doctors and the nurses, the social workers, the case managers that take care of this population is very important. And we cannot minimize these types of things as Ana Garcia has pointed out so well this morning, in terms of the costs of taking care of HIV infected children.

Thank you, very much.

[Prepared statement of Philip Plummer follows:]

## PREPARED STATEMENT OF PHIL PLUMMER, ADMINISTRATOR, SOUTH FLORIDA AIDS NETWORK, JACKSON MEMORIAL HOSPITAL, MIAMI, FL

In order to fully appreciate the impact of AIDS in children one must understand that for every HIV infected child that we identify we are also identifying an HIV infected mother, (98% of the children with HIV currently being cared for at Jackson Memorial Hospital have been infected through perinatal transmission). Within our pediatric AIDS Demonstration Project the following data has been collected on a sample of one hundred HIV positive mothers.

- Racial/Ethnic breakdown:
  84% Black (of which 27% are of Haitian origin)
  14% Hispanic
  2% White

- Age ranges are between 13 and 46 of which:
  5% are under the age of 19
  22% are between the ages of 19 and 21
  73% are between the ages of 25 and 46 years of age

- Marital status is:
  77% are single
  19% are married
  3% are divorced
  1% are widowed

18% of the mothers enrolled in this project admit to substance abuse, (drugs of choice include crack, intravenous drugs and alcohol)

2.1% of the babies delivered at JMH (for 14,000 deliveries) are of HIV infected mothers.

The cost of care of HIV infected children therefore must begin with the cost of testing and counseling pregnant women for possible HIV infection. The cost of providing this basic initial service is estimated to be $1,000,000, ($71.42 per client).

A second cost factor involved for care of HIV infected children also occurs prior to the birth of the child. This cost includes:

-Providing the identified HIV infected expectant mother with intensive prenatal care. These expectant mothers should receive a minimum of 90 prenatal visits during the course of their pregnancy.

-Providing identified HIV infected expectant mothers who are substance abusers with a rehabilitation program or at minimum a safe space where they will be drug free during the remainder of their pregnancy. Currently there are no substance abuse treatment programs that will accept a pregnant women. if there were the waiting list for a person entering a program would prohibit intervention prior to the delivery of the child. at an estimated cost of $60.00 per day per client x 120 days of treatment, the annual cost of treatment for this population is projected to be $390,000

-Providing a nutritious, balanced diet for all identified HIV infected expectant mothers.

Once a child is born to an HIV infected mother there is the necessity of providing medical follow-up to that child to determine the child's HIV status. An affirmed HIV status can be determined somewhere between 18 months and two years of age. Serial HIV testing must be available during this period which include T cell counts. An estimated 25 to 40% of the children born of HIV infected mothers will themselves be HIV infected. Until the HIV status of the child is determined it must be assumed that he/she is HIV infected. Everybody colds, flues, ear aches etc. that children experience must receive prompt medical attention.

The cost of care for an HIV infected child is outlined in attachment #1. These costs include inpatient care, outpatient clinic visits, foster care and home health care.

If a child is born drug addicted in addition to being HIV infected you can factor in an estimated 25% increase in these items.

The cost of caring for an HIV infected child goes well beyond the immediate needs of the child. The emotional impact on the caregiver must also be considered.

## PEDIATRICS STATISTICAL ANALYSIS REPORT

## INPATIENT CARE

*** Cover 6 months period of time 1989**

| YEAR | NUMBER OF PATIENTS | LENGTH OF STAY | CHARGES | AVG. LENGTH OF STAY | AVG. COST PER PATIENT | AVG. DAILY COST |
|---|---|---|---|---|---|---|
| 1987 | 45 | 1452 | 858772.40 | 32 | 19084.00 | 591.00 |
| 1988 | 65 | 3106 | 2762006.84 | 48 | 42492.00 | 889.00 |
| *1989 | 48 | 1036 | 1136577.00 | 22 | 23679.00 | 1097.00 |

## OUTPATIENT CARE

| YEAR | NUMBER OF PATIENTS | NUMBER OF VISITS | CHARGES | AVG. NUMBER OF VISITS | AVG. COST PER PATIENT | AVG. COST PER VISIT |
|---|---|---|---|---|---|---|
| 1987 | 132 | 299 | 30892.99 | 2 | 234.00 | 103.00 |
| 1988 | 167 | 580 | 98487.00 | 3 | 590.00 | 170.00 |
| 1989 | 148 | 421 | 63569.00 | 3 | 430.00 | 151.00 |

## FOSTER CARE

| YEAR | NUMBER OF PATIENTS | LENGTH OF STAY | CHARGES | AVG. LENGTH OF STAY | AVG. COST PER PATIENT | AVG. DAILY COST |
|---|---|---|---|---|---|---|
| 1987 | 9 | 766 | 37292.69 | 85 | 4144.00 | 49.00 |
| 1988 | 40 | 5993 | 347770.57 | 150 | 8694.00 | 58.00 |
| 1989 | 29 | 3957 | 267983.91 | 136 | 9241.00 | 68.00 |

## HOME HEALTH CARE

| YEAR | NUMBER OF PATIENTS | LENGTH OF STAY | CHARGES | AVG. LENGTH OF STAY | AVG. COST PER PATIENT | AVG. DAILY COST |
|---|---|---|---|---|---|---|
| 1987 | 20 | 532 | 28141.08 | 27 | 1407.00 | 53.00 |
| 1988 | 29 | 820 | 40824.62 | 28 | 1408.00 | 50.00 |
| 1989 | 28 | 914 | 23368.33 | 33 | 835.00 | 26.00 |

Chairman **Miller**. Thank you. Let me ask you, we should be adding these columns, right?

Mr. **Plummer**. That is correct.

Chairman **Miller**. In patients should be added to later out-patient costs should be added to later foster care, should be added to later home health care.

Mr. **Plummer**. That is correct.

Chairman **Miller**. Okay.

Mr. **Plummer**. Obviously, though the numbers of foster children needing foster care at this point in time is much smaller than those numbers of children needing out-patient care.

Chairman **Miller**. Right, but in——

Mr. **Plummer**. Potentially——

Chairman **Miller** [continuing]. The children can move between these populations and these are expected costs that we should be looking at.

Mr. **Plummer**. That is correct.

Mr. **Lehman**. If they survive.

Mr. **Plummer**. If they survive, right. A child who survives his own mother's ability to care of him, will probably fit into this foster care component. Once a mother gets too sick or dies, we are going to wind up with another child who potentially needs foster care.

Chairman **Miller**. Thank you. Dr. Laureano-Vega.

Dr. **Laureano-Vega**. Good morning.

Chairman **Miller**. Good morning.

## STATEMENT OF MANUEL LAUREANO-VEGA, M.D., EXECUTIVE DIRECTOR, LEAGUE AGAINST AIDS, MIAMI, FL, ACCOMPANIED BY MIREILLE TRIBIE, M.D., ASSISTANT DIRECTOR, LEAGUE AGAINST AIDS, MIAMI, FL

Dr. **Laureano-Vega**. We appreciate the opportunity to share some thoughts with you regarding Hispanic, Haitians and the AIDS crisis about what we have learned and what challenges still lie ahead. We are members of the minority community and as such we serve as advocates for our people, specifically with regards to issues surrounding AIDS.

We have worked in this community during the last three years, during which we have been instrumental in the establishment of AIDS educational and prevention, as well as psychosocial service programs, such as the Educational Department of the South Florida AIDS Network, the Minority AIDS Program at the Haitian American Community Association of Dade, HACAD, and the only minority AIDS service organization of Southern Florida, the League Against AIDS, called Liga Contra SIDA in Spanish.

On the national scope we have provided guidance and support for programs targeting our communities in collaboration with agencies such as the National Hemophilia Foundation, the National Minority AIDS Counsel, the Bureau of Maternal and Child Health, the National American Red Cross, and, the Centers for Disease Control, just to name some.

We have been asked to shed some light on the impact of the AIDS epidemic on the Haitian and Hispanic communities with respect to the following topics: Pediatric AIDS; the problem of HIV infection in illegal aliens; the necessity for coordinating the medial and psychosocial care; and, what previous educational and preventive initiatives have been designed for our community.

Let us briefly review with you some facts about who we are in order to place the AIDS issue in perspective. There are approximately 869,100 Hispanics and 80,000 Haitians in Dade County. We live in the area of the State which represents the highest incidence of diagnosed AIDS cases in Florida. It may be important to recognize that the Hispanic population in Dade is a mosaic composed of several Hispanic subcultures, among them Cubans, Puerto Ricans and Central or South Americans.

Along with many Hispanics, the majority of the Haitians have immigrated to this country for both political and economical reasons. We are generally a younger age group than that of the United States population as a whole. We place a high value on the family and on the children. This is particularly true in the segment of our population which is illiterate and dependent on the family structure for assurance of well being during retirement.

We hold onto traditional values of our respective subcultures and countries of origin. Approximately three-quarters of us regularly would prefer for our children, we would prefer to use the Spanish or Creole languages. Over half of us would like our children to develop fluency in our mother tongue. As a people we heavily depend on the church and the home to transmit cultural, ethical and moral values.

Parents and elders are held in high esteem and respected through one's lifetime. We depend heavily on certain mediums of communication to get our information, particularly television and radio, and to a lesser extent the printed media.

We are generally a proud people who work hard to provide a better life for our future generations in this country. We are by and large resourceful and take pride in taking care of our own within the conflicts of the family and the community. In times of crisis we seem to truly show our very best attributes of compassion, caring and unequaled devotion to anyone in la familia, and that includes the extended family concept.

We have learned about AIDS. What we have learned about AIDS and its impact on our communities in the last 10 years is a lot. Let's go through this.

AIDS is perceived differently by Hispanics and Haitians. Initially it was thought to be a White gay disease and still is the case in many instances. Our people have difficulties identifying with AIDS as a potential risk to them, or to their families.

It is difficult to discuss AIDS openly with a large segment of Hispanics and Haitians, because of certain taboos on sexual subjects. Because of the issue of homosexuality and the issue of denial. There is difficulty among our people understanding a long incubation period and modern biomedical germ theories, or concepts that a behavior engaged in tonight might potentially place anyone at risk for developing AIDS five to eight years down the line.

Individuals in our community appear to wait until the last minute to see a physician or enter the health care system. The use of AIDS culturally appropriate poultices are reasons that the members of our community die faster after a diagnosis of AIDS than the White Anglo patient, and the differences here are striking as six months versus two years. Information on how and when to access appropriate health care on a timely basis is desperately needed.

There does not appear to be large number of credible health care providers that are trusted by our people with who they can be frank and open about their sexual orientation or behaviors, or that can impact necessary risk reduction information without being judgmental.

Our people have difficulty in accessing bilingual/bicultural health care that is responsive to their perceived needs, as well as to the needs of their families and significant others in this regard. There appears to be considerable reluctance on the part of certain key and influential members our community, as well as some elected officials, to be associated with the AIDS issue. By and large the Hispanic physician has been essential, essentially quiet during this crisis and only a few of them have become spokespersons or advocates at a time when they need most to be heard in order to save lives.

What kind of approach we have utilized in view of recognizing that the results are yet to be measured and require more documentation, further study and research.

Our approach in the AIDS issue among our people, must be one that is solely motivated by the desire to save lives and reduce the number of persons from our community who will become infected. Although the AIDS issue has, and will continue to be politicized, and some of us may genuinely be more interested and contributory in the political arena of AIDS, the greatest challenge and need is in educating and informing our community and consequently saving lives.

AIDS prevention and educational messages must be given simply stated terms within culturally relevant parameters, utilizing tried and true concepts of health education and health behavior change. The message must be clear and concise and given by credible professional people, who can personally and sensitively relate to target audiences. the audience must perceive that I too am vulnerable and that our message has applicability to me as well as to you. Any of us could be potentially at risk for this disease.

Our audiences must be reached in natural settings within community churches, schools and work sites, preferably and not in special forums or community conferences for AIDS. There is a tendency to not want to be seen attending these for obvious reasons.

There must not by any further alienation or stigmatization of our Hispanics and Haitians because of AIDS. It is no longer important to be classifying or labeling individuals as members of any high risk group. The message must be loud and must be clear, I do not need to be gay, a drug user or promiscuous to get AIDS, rather the emphasis must be placed directly on being perfectly honest and up front with our audiences. Any one of us who has engaged or is currently practicing specific sexual behaviors, may be placing themselves at risk for AIDS.

We have to gain a better understanding of drug use in our communities. We have to listen to persons with AIDS and the difficulties which face both the single individual and the family system. We need to find innovative ways of addressing the issue of denial within our community. There has got to be an opportunity for individuals to inquire about AIDS and risk reduction practices in a confidential and appropriate manner.

There is a dire need for anonymous testing and counseling for our people, anonymous. Many, who will generally resist going to sites within our program which are sponsored by the gay community or governmental agencies, or by sites that do not have bilingual/bicultural staff, probably would go somewhere where they feel safe.

We have generally a desire within the family to care for their own who have AIDS, yet we have a lack of organized ways of assisting HIspanic and Haitian families to do a better job of caring for their loved ones with AIDS.

Our Hispanic and Haitian communities must have access to alternative therapies and experimental protocols, at major medical centers. These are most difficult for many of our communities to access. Our people need to also be introduced to alternatives for living with AIDS including home health care, respite and hospice care, constant, which are foreign in our community.

We must provide Hispanics and Haitians the opportunity to participate at Federal, State and local levels in the development of appropriate strategies to educate and provide services to our own people.

These are but a few things that we have learned over the past years about Haitian and Hispanic communities and their response to AIDS in this crisis. You will find that AIDS influences each ethnic minority, in many of the same respect that it influences the majority. That we have added on crisis.

Chairman MILLER. Dr. if you can, if I can ask you to summarize the written testimony, so we will have a chance to ask you some questions.

Dr. LAUREANO-VEGA. Basically the rest is emphasizing that with AIDS comes some very very specific issues. They are particular pertaining to loss, AIDS is synonymous with loss, you have loss of your physical and emotional well being, your family structures, and great amounts of stress are created which contribute to the falling apart of institutions which our communities need in order to survive, the already overwhelming stress that they are going through.

Adequate resources are not available for our community to institute and mobilize the resources that are at hand, but are not available, so that we can adequately deal with the crisis.

And in the last part of my testimony, we have some prior services which have been provided by our agency in a very limited fashion to this community, because it is a small agency and it is a large community. But with appropriate resources, we will be able to expand on these very needed efforts of mobilization within our community.

[Prepared statement of Laureano-Vega, M.D., follows:]

## PREPARED STATEMENT OF MIREILLE TRIBIE, M.D. AND MANUEL LAUREANO-VEGA, M.D., EXECUTIVE DIRECTOR, LEAGUE AGAINST AIDS, MIAMI, FL

MEMBERS of the Select Committee on Children, Youth, and Families of the U.S. House of Representatives.............GOOD MORNING..........
We appreciate the opportunity to share some thoughts with you regarding Hispanics, Haitians and the AIDS Crisis, about what we have learned , and what challenges still lie ahead. We are members of the Minority community and as such were serve as advocates for our people specifically with regards to Issues surrounding AIDS. We have worked in this community during the last three years during which we have been instrumental in the establishment of AIDS educational and prevention as well as psychosocial service programs, such as: The Educational Department of the South Florida AIDS Network, the Minority AIDS Program at the Haitian American Community Association of Dade (HACAD), and the only Minority AIDS Service Organization of Southern Florida the League Against AIDS ( Liga Contra SIDA). On a national scope we have provided guidance and support for programs targeting our communities in collaboration with agencies such as The National Hemophilia Foundation, The National Minority AIDS Council, The Bureau of Maternal and Child Health, The National American Red Cross, The Centers for Disease Control, just to name a few.

We have been asked to shed some light on the impact the AIDS epidemic is having on the Haitian and Hispanic Communities with respect to the following topics:

1. Pediatric AIDS in the Hispanic and Haitian Communities.
2. The problem of HIV infection for illegal aliens ineligible for medical care, social services and public assistance.
3. The necessity for coordinating medical and psychosocial care for HIV-positive individuals.
4. Educational and Preventive initiatives designed for these Communities.

Let us briefly review with you some facts about who we are in order to place the AIDS issue in perspective. There are approximately 864,100 Hispanics and 80,000 Haitians in Dade County. We live in an area of the state which represents the highest incidence of diagnosed AIDS cases in Florida. It may be important to recognize that the Hispanic population in Dade is a mosaic composed of several Hispanic subcultures among them Cubans, Puerto Ricans, and Central or South Americans . Along with many Hispanics, the majority of Haitians have immigrated to this country for both political and economical reasons. We are generally a younger age group than that of the United States population as a whole. We place a high value on the Family and on children. This is particularly true in the segment of our population which is illiterate and dependent on the family structure for assurance of well being during retirement. We hold on to traditional values of our respective subcultures and countries of origin. Approximately three quarters of us regularly us or prefer to use the Spanish or Creole languages. Over half of us would like our children to develop fluency in our "Mother tongue" As a people we depend heavily on the Church and the Home to transmit cultural, ethical and moral values. Parents and elders are held in high esteem and respected through ones lifetime. We depend heavily on certain mediums of communication to get our information particularly television and radio, and to a lesser extent the printed media. We are generally a proud people who work hard to provide a better life ,for our future generations, in this country. We are by in large resourceful and take pride in taking care of our own within the context of the family and the community. In times of crisis we seem to truly show our very best attributes of compassion, caring, and unequaled devotion to anyone in" la Familia" and that includes an extended family concept.

What have we learned about AIDS and its impact on our communities in the past years?

1. AIDS is perceived differently by Hispanics and Haitians. Initially it was thought to be a White Gay Disease and this is still the case in many instances.
2. Our people have difficulties identifying with AIDS as a potential risk to them,or their families.
3. It is difficult to discuss AIDS openly with a large segment of Hispanics and Haitians because of certain tabus on sexual subjects, because of the issue of Homosexuality and the issue of denial.
4. There is difficulty among our people understanding a long incubation period, modern biomedical germ theories or the concept that a behavior engaged in "tonight" might potentially place anyone at risk for developing AIDS five to eight years later.
5. Individuals in our community appear to wait until the "last minute" to see a physician or enter the health care system, the use of culturally appropriate poultices are reasons that the members of our community die faster after a diagnosis of AIDS than the white Anglo patient (six months vs. two years). Information on how and when to access appropriate health care on a timely basis is desperately needed.
6. There does not appear to be large numbers of credible health care providers that are trusted by our people with whom they can be frank and open about their sexual orientation or behaviors or that can impact necessary risk reduction information without being judgmental.
7. Our people have difficulty in accessing bilingual-bicultural health care that is responsive to their perceived needs as well as to the needs of their families and significant others in this regard.
8. There appears to be considerable reluctance on the part of certain key and influential members of our community as well as some elected officials to be associated with the AIDS issue. By and large the Hispanic physicians have been essentially quiet during this crisis and only a few have become spokespersons or advocates at a time when they need most to be heard in order to save lives.

What kind of approach we have utilized in view of this recognizing that the results are yet to be measured and require much more documentation, further study and research.

Our approach in the AIDS issue among our people must be one that is solely motivated by a desire to save lives and reduce the number of persons from our community who will become infected. Although the AIDS issue has and will continue to be politicize, and some among us may genuinely be more interested and contributory in the political arena of AIDS, the greatest challenge and need is in educating and informing our community and consequently saving lives.
Aids prevention and educational messages must be given simply stated

terms within culturally relevant parameters, utilizing tried and true concepts of Health education and health behavior change. The message must be clear and concise and given by credible and professional persons who can personally and sensitively relate to the target audience. The audience must perceive that, I too am vulnerable and that our message has applicability to me as well as you. Any of us could be potentially at risk for AIDS.

Our audiences must be reached in natural settings within our community Churches, schools, and work sites, preferably and not at special forums or community conferences for AIDS.
There is a tendency to not want to be seen attending these for obvious reasons. There must not by any further alienation or stigmatization of our Hispanics and Haitians because of AIDS. It is no longer important to be classifying or labeling individuals as members of any High-risk group. The message must be loud and clear." I don't need to be gay, a drug user, or promiscuous to get AIDS". Rather the emphasis must be on being perfectly honest and upfront with our audiences--any one of us who has engaged or is currently practicing specific sexual behaviors, may be placing ourselves at risk for AIDS.

We have to gain better understanding of drug use in our communities. We have to listen to persons with AIDS and the difficulties which beface both the single individual and the family system. We need to find innovative ways of addressing the issue of denial within our community. There has got to be an opportunity for individuals to inquire about AIDS and risk reduction practices in a confidential and appropriate manner. We have successfully implemented a Spanish/Creole language Hotline in Miami which in the future may become part of a larger local effort to provide this needed service to the community. There is a dire need for anonymous testing and counseling for our people many who will generally resist going to sites within or sponsored by the gay community, or by governmental agencies, or by sites that do not have bilingual /bicultural staff.
We have found generally, a desire within the family structure to "care for their own " Who have AIDS, yet we have a lack of organized ways of assisting Hispanic and Haitian families to do a better job of caring for their loved ones with AIDS.

Our Hispanic and Haitian communities must have access to alternative therapies and experimental protocols a the major medical centers--these are most difficult for many in our community to access. Our people need to also be introduced to alternatives for living with AIDS including Home health care, respite and Hospice care.

We must provide Hispanics and Haitians the opportunity to participate at federal, state and local levels in the development of appropriate strategies to educate and provide services to our own people.

These are but a few things learned over the past years about the Hispanic and Haitian communities response to our communities AIDS crisis.

Aids is a unique disease in that it presents each community with some basic problems which could be considered universal. The Impact of Aids on specific racial and ethnic communities varies to the extent of the differences in cultural values which characterize the individual subcultures which compose our great nation.

The impact which the AIDS epidemic is having on the Haitian and

Hispanic families can be classified into the following categories. Personal, Social, Political and Legal.

Personal impact

The physical and psychological integrity of the individuals which compose the family systems are threatened. There is a variety of physical and psychological losses. So central to AIDS is the concept of loss that it becomes the central fixation point of the individual or the family.
The physical losses be it an adult of a pediatric case include
1. loss of energy
2. loss of strength
3. loss of appetite
4. loss of motility
5. loss of basic physiological functions such as bladder and bowel control

We also see neurological complications which result in additional losses such as
1. loss of speech
2. loss of cognitive ability
3. loss of sensory functions among theses
    a. sight
    b. hearing
    c. and tactile sensations

Many other complications brought on by the side effects of medications contribute to the losses which the family must cope with.

A person with AIDS as well as the rest of his or her family unit must learn to deal and accept the multiple psychological losses---physical stamina, body image, mental clarity, privacy, self sufficiency and personal competency.

The life, future hopes and dreams of these individuals are threatened. The interpretations of new symptoms that once might have been ignored becomes anxiety provoking since these new symptoms may indicate a new infection or signify the progression of the disease.

A number of fears befall on the family members of a pediatric or adult AIDS case. These include fear of the unknown ( what will happen next, will it happen to me or to my baby first), fear of death and dying( who will die first, myself or my baby) How difficult it must be for a parent to see his or her baby die and then face eminent death themselves. Fear of loneliness, the fact that we have seen families virtually eliminated makes one contemplate how these individuals must feel as they watch the demise of their family due to HIV infection. Fear of abandonment (not only by close friends but also by the community), We have witnessed the death of families in solitude except for the support they may receive from the scarce psychosocial agencies such as ours. Fear of sorrow, not only the grief provoked at the thought of ones own mortality, but that of a loved one. Fear of guilt, specially a mother or father who may feel very much responsible for the fate of their offspring. Fear of dependency and regression, AIDS is an expensive disease, many individuals of Minority origin do not have the economic resources to adequately manage this impact. Many families succumb to the economic pressures of their situation becoming totally dependent on social systems that are not prepared to meet their needs.
Consider the impact of AIDS on a persons life: The individual must

change lifestyles and behavior, reexamine priorities and aspirations, cope with complex medical systems and learn how these function. and establish relationships with care takers. The individual has to deal with the pain and incapacitation of themselves and eventually the family structure on which they rely, and adjust to changes in their external reality--- relationships with other family and friends, income, perhaps social and employment roles. The fact is that this disease is considered to be a homosexual disease or that of I.V. Drug users, not uncommonly this brings up reactivation of internalized negative feelings towards homosexuals, and in others internalized homophobia and fear towards prejudice. These events often result in lowered self esteem, depression, guilt and self blame of having become infected with HIV and having transmitted it to a spouse or child.

The social impact of the AIDS epidemic extends itself in a largely multifaceted problem in the Hispanic and Haitian Communities. Countless incidents of people who are being evicted from their homes, loosing their jobs, being abandoned by friends attest to the sociological phenomenon which surrounds this disease. These issues coupled with additional political issues faced by those HIV positive individuals seeking residency status in the United States create a tetric scenario. The Life style characteristics of those initially at highest risk for this disease create and stimulate emotional reactions from the community. Because of this erroneous perception within our communities, Individuals with AIDS and their families may be subjected to fear ,hatred, and prejudice which may be blatant or covert. This diagnosis with in a family system forces it to be exposed to and environment that already may be hostile.

The political and legal implications of AIDS are also complex. Discussions regarding deportation of HIV positive aliens or refugees, the denying of residency status to individuals applying through Amnesty, Haitian/Cuban Entrant, and Migrant farmworker programs because of their HIV positive status is a disgrace. The possibility that these individuals were infected in this country and that this country offers the highest hope for cure or treatment of this disease cannot be overlooked. Yes, the problem is there but we must apply constructive measures to cope with it appropriately. One does not pick up the problem and export it to another county whose public health services, educational and prevention programs are rudimentary or nonexistent. This would equate to devastation of neighboring populations who already have a problem on their hands let alone receive tens of thousands of infected deportees.

Many of Minority individuals do not have good access to medical care( they cannot afford it) social services( they are not eligible) and public assistance programs. Many of our people have been here for a number of years and have paid into systems which now they can not tap into.

Prior Services provided:

The League has established a two pronged approach to assist the Hispanic and Haitian communities in Dade and Broward Counties on the issue of AIDS: Education/Prevention and Counseling. Prevention information seminars and activities are conducted upon request. Information in the form of written and graphic materials aimed at higher risk group are distributed along with risk reduction packages that include condoms, to members of the following group: general community, homosexual and bisexual men, the sexual partners of those previously mentioned, teenagers, and women.

Information regarding AIDS, its modes of transmission and particularly the dangers of contracting the disease is provided to organizations composed mainly of minority individuals, i.e. social service groups such as Kiwanis Clubs, and at events such as the annual Calle Ocho Festival. More formal and structured presentations are available to professional groups that service the racial and ethnic minorities of Southern Florida (HMO's, Medical Associations, etc.) Many of the activities of the League with regards to the education/prevention aspects of our program are based on mass media dissemination of Risk Reduction information. The favorite and most effective mass media tool for Hispanics and Haitians are television and radio. On both these media forms we have employed comprehensive educational programming. The League has strongly established its credibility with the media (radio and television) and local newspapers. Over the past two years we have appeared on numerous radio and television shows with the purpose of educating the public about AIDS and the League's intentions. The program formats are talk shows with question and answer segments where the viewer or listener may call in their questions.

The content of the programming usually include the following:

1. Culturally linked facts about AIDS and AIDS transmission;
2. HIV infection and the spectrum of disease;
3. Religious issues and AIDS;
4. Sex, AIDS, and the Adolescent;
5. AIDS, family values, and communication within the Hispanic and Haitian communities;
6. "Say No" to sexual promiscuity and drugs; if you can not, then engage in safer sexual and drug usage practices.
7. Hispanic and Haitian children and women with AIDS.
8. Risk Reduction strategies and AIDS.

The use of AM radio includes programming whose sole purpose is awareness raising. We have developed four different 30 second public service announcements that are being aired. The Hispanic AIDS awareness motto is "Do not die because of ignorance!" -- "No mueras por ignorancia!". As part of this programming we have created a twenty minute audio tape. This tape is used in an hour long program with a question and answer format. The first twenty minutes are (pretaped) general AIDS information and then a Health Educator answers any questions during a 40 minute call-in period.

We have designed a series of 60 second informational messages aimed a dispelling myths within the Hispanic community. This project called "Capsulas sobre el SIDA" is suitable for both AM and FM radio stations and targets the younger Hispanic groups Some of the stations which have sponsored our efforts in this area are:

| | | | |
|---|---|---|---|
| 1. | WQBA | 1140 AM | (Spanish) |
| 2. | Super Q | 106.7FM | (Spanish) |
| 3. | WCMQ | 1210 AM | (Spanish) |
| 4. | WCMQ | 92 FM | (Spanish) |
| 5. | WRHC | 1550 AM | (Spanish) |
| 6. | WOCN | 1450 AM | (Spanish) |
| 7. | WLQY | 1320 AM | (Creole) |
| 8. | WVCG | 1080 AM | (Creole) |

The League Against AIDS has been involved with the conceptualization and planning of the CDC's National Mailer and Television Public Service announcement campaign "America Responds to AIDS". We presently use these Public Service announcements to promote our Spanish/Creole Language AIDS hotline, on Channel 51 and Channel 23, Hispanic International Television Cable Network and all the above mentioned radio stations.

The League has access to many nationally televised Hispanic variety shows on the Univision and Telemundo television networks (National Hispanic Networks). On various occasions the League has done educational segments in programs of the caliber and high ratings as: Dia a Dia (4:00 PM Prime time) and Sabados Gigantes (The most watched Hispanic National TV Program). The League has also participated in the production of three national documentaries: AIDS LIFELINE promoted and produced by Metropolitan LIFE, SIDA is AIDS the first Hispanic National documentary produced by KCET and UNIVISION, and recently the production of the third, which focused on AIDS in the Minority communities produced by PBS television of Maryland, providing information and expertise about the AIDS crises within the Haitian and Hispanic communities.

The League has also done a campaign on the local cable television networks, HIT TV (Hispanic International Television) which primarily broadcast to the Hialeah area in Dade County. We have produced local TV programming in which members of the League introduce the concepts of Risk Reduction to the Hispanic viewers of this predominately Hispanic area.

The League is presently working with the CDC funded Dade County Public Schools AIDS information and Education Program. We are members of their speakers bureau and frequently present culturally sensitive lectures in Spanish, Creole, and English that attempt to reach the assimilated and non-assimilated non-anglo student and parent. The school system's presentations are delivered on school grounds to groups of students from the 5th, 7th, 10th, and 12th grades. The parents are reached through adult education programs and PTA meetings. In addition, The League sits on the DCPS Material Review Committee. In an ongoing process to maintain a high level of educational material in Southern Florida. The League's education department actively reviews and identifies appropriate AIDS materials for use within the schools.

In an effort to assist in the decision making process with regard to pressing AIDS issues in the public school setting, we are members of the DCPS AIDS Task Force. The DCPS's curriculum on AIDS education is revised every two years. Last year the League served on the curriculum review process. The alliance that the League Against AIDS enjoys with the DCPS AIDS Information and Education Office is comprehensive. We participate in their special teacher and administrative training and in their special educational programs. Lastly, the DCPS has a cable television station that the League on numerous occasions has participated with by way of delivering preventive messages through the educational television airwaves. We have also participated and helped produce a local behavior change video tape programming based on presentations of positive role models and risk reduction messages which targets senior high school students of Dade.

Networking with the State AIDS Program located in District X (DADE) the League presently holds seats on the State's Material Review panel for both the Hispanic and Haitian communities in an attempt to maintain high quality and cultural specificity and sensitivity within the total of the AIDS educational materials utilized and distributed by the State of Florida. We also receive materials for distribution from the State these include: Pamphlets, Brochures, and Condoms.

In cooperation with the American Red Cross, the League has delivered education programs to Corporations, Migrant Farmworker groups, and health care workers as part of their "Beyond Fear" Program. The League holds a seat on the Miami ARC Chapter AIDS Advisory Committee, and also works in cooperation with ARC Headquarters in Washington as part of the National AIDS advisory committee for Hispanic Youth and Family. We are presently collaborating with the production of the New ARC Hispanic AIDS Educational Materials, and will be actively involved with the field testing of these materials in the Dade area.

The League, The American Red Cross, The Dade County Public Schools and the National PTA recently collaborated in the production of an AIDS Awareness raising poster of the Haitian Community. The League is also directly involved with major Haitian coalitions which address issues pertaining to Haitian women and immigrants.

The Haitian Program for Youth and Family of the League Against AIDS, Inc. is presently involved with educational interventions targeting Haitian women in environments which are culturally suitable for delicate AIDS risk reduction information dissemination. This program is a pilot presently funded by the United States Conference of Mayors which is having excellent success and acceptance by the women of the Dade and Broward County areas. This contract entails the making of presentations to groups of women, for example, a beauty parlors; the production of television and radio shows as well as radio PSA's aimed at women; as well as the development of educational materials in Creole.

This program is also delivering AIDS preventive messages to other Haitian Community groups such as: Haitian churches, Technical/Vocational schools, and health related training institutions which have high percentages of Haitian students. During these presentations we use audiovisual material such as; "Se Met Ko", a culturally sensitive Creole video tape and after a brief presentation the Haitian Health Educator entertains questions and answers in an attempt to process emotional issues made evident during the workshop.

As described in the Needs Assessment, AIDS education and counseling among Haitians is a particularly sensitive area. This is because of the devastating effects the recent publicity generated by the disease has had upon the community, because of entrenched Haitian beliefs and attitudes concerning the disease, because of Haitian tendencies toward denial, because of Haitian attitudes towards sex and discussion of sexual matters, and because of the unfamiliarity of many Haitians with modern biomedicine. The League has created a program of counseling and education that addresses these issues and depends, for its effectiveness, upon an appeal to basic Haitian values and upon a method of delivery based on typically Haitian styles of communication. For example, one basic Haitian value is that of having children, as a validation of adulthood and of marital union, as a mainstay of the household, as an insurance against old age, and as the source of family continuity. The League's educators and counselors emphasize this value in describing the risks of unsafe sex. Haitians also value the ability to work hard, earn a living, and regard good health as prerequisite to this end. Again, counselors or educators appeal to this value in teaching ways of maintaining good health. By doing so, they not only attempt to change beliefs, but to guarantee that behavior change will follow, such behavior having been transformed into an expression of fundamental Haitian values.

The League's client services department offers an array of direct and indirect client and family assistance. This assistance program addresses their medical, educational, and counseling needs. We have established this program with the use of professional staff and trained volunteers who provide service to the client and family upon request. We also provide the liaison and referral service to the South Florida AIDS Network throughout the duration of our program. The counselors work in conjunction with comprehensive case management system of the South Florida Aids Care and Treatment Network, which is based at Jackson Memorial Hospital. The counselors make home-visits to the League's clients who are unable to come to the agency for counseling. The program is implemented on daily and nightly basis in order to ensure access to PWAs who work or have structured day schedules. The League has programmed to establish a pediatric PWA day care project that will alleviate the stress and overwhelming responsibilities that befall the family members. In addition to providing day care, the League has instituted a structured management program for participants.

Presently, the League Against AIDS Client Services Department maintains a counseling ease load of 125 individuals with AIDS. The caseload profile is distributed in the following way:

| **Sex** | **Transmission** | **Ethnicity** |
|---|---|---|
| Male-86% | Homo/Bi -49.5% | Hispanic - 60.68% |
| Female-14% | Hetero - 41.8% | Haitian - 29.01% |
|  | I.V. - 5.9% | Am. Black - 5.09% |
|  | Hemo - 1.0% | White Anglo - 3.04% |
|  | Pedi - 1.0% | Trinidad - 1.0% |

Patient/Family Education Services presently being provided in group and one-on-one settings include:

1. **Medication Management Group** where the group is broken down into subgroups of individuals using the same medications. Classes will focus on:

    a. Posology/Dosages
    b. Food/Drug Interactions
    c. Drug/Drug Interactions
    d. Adverse Side Effects
    e. Drug Tolerance Skills

    Nurse volunteers and medically trained staff members present this information.

2. **Basic Fundamental Immunology** - Information is given to all program participants. The nature of AIDS requires that clients (PWAs) understand the basic function of the immune system, how to fortify it, and prevent recurring infections. This is provided by medically trained staff.

3. **National and Local Protocol Update** - where clients are kept abreast of available experimental drugs and regimens. This is provided by staff and professional volunteers from the special immunology laboratory of the University of Miami.

4. **Nutritional Information** - people with AIDS require an appropriate intake of calories, vitamins and minerals to insure optimal health status. The ethnic diversity among the PWA's population necessitates the development of culturally sensitive diet plans. Consulting nutritionists supervise, train and assist volunteers in providing this service.

**Psychosocial Counseling Services included:**

1. **Psychosocial Support Groups** - that in place for Haitians and Hispanics focus on issues of:

    a. Sexuality
    b. Risk Behavior
    c. Family Dynamics
    d. Death and Dying
    e. Bereavement
    f. Coping Skills
    g. General Life Enhancement Skills

    This service is provided by professional counseling staff, supervised by the Assistant Executive Director both in Creole and Spanish.

2. **Visualization Sessions** - where clients are guided to envision the process of their minds and bodies. The League stresses holistic approach through supportive counseling of PWAs and their families. Visualization therapists provide the above.

3. **Gentle Exercise and Body Movement Therapy** - is geared towards cardiovascular stimulation and overall physical fitness. This program serves to teach PWAs and family members stress management through exercise. Staff and trained volunteers provide the above.

4. **Stress Management/Relaxation and Meditation** - augments our holistic approach to health management of the PWAs and family members. Trained staff and volunteers provide the above services.

5. **Spiritual Enhancement** - provided via services (mass) conducted by chaplains from neighboring churches. The spiritual component ensures the completeness of our holistic therapeutic intervention program that encompasses the mind, body and spirit.

6. **General Recreation** - clients enjoy movies, picnics, and other recreational activities coordinated by staff.

7. **Transportation** - clients profit from free transportation to and from our facility, social service agencies, and recreational sites.

Psychosocial counseling is also provided by our staff on a one-on-one basis to each client by request. This service allows individuals to access the support from their counselors directly when they feel that issues are too sensitive to be discussed in group sessions, or due to their particular personalities, they do not wish to attend a support group.

The League Against AIDS, Inc. holds a seat on the National Minority AIDS Council Board of Directors, and also holds a Co-Chairman position with the National Latino AIDS Caucus.

The League Against AIDS, Inc. is a small non-profit Minority AIDS Service Organization that has a staff composition 100% of minority origin. We are 50% Hispanic and 50% Haitian by ethnic distribution. The staffing needs of the agency with regard to the epidemic in our area are great. We are managing on the resources presently available but with an increase in staff we will be able to amplify its capacity to provide sensitive and specific education and outreach which responds effectively to the cultural, environmental, social and multilingual character of our large populations.

Chairman MILLER. Thank you. Dr. Tribie, are you going to testify, are you here to respond to questions?

Dr. TRIBIE. No, I am here to respond.

Chairman MILLER. Okay, fine. Dr. Miller.

## STATEMENT OF REV. DR. ROGER P. MILLER, CHAPLIN IN AIDS MINISTRY, AND CHAIRMAN OF MIAMI AIDS INTERFAITH NETWORK, MIAMI, FL

Dr. MILLER. Mr. Chairman, Congressman Lehman and Congressman Durbin, members of the Select Committee and other distinguished guests, I thank you for the opportunity to testify on behalf of some of the most vulnerable of American citizens, those babies and children infected from birth with the Human Immune Deficiency Virus.

As Chairperson of the Miami AIDS Interfaith Network, the Senior Chaplain in AIDS Ministry here at the University of Miami Jackson Memorial Hospital, and as an experienced pastor, educator and counselor for a number of years, I am delighted that your esteemed group has decided to address not only the medial and legal issues of pediatric AIDS, but the ethical, moral and spiritual issues that this epidemic brings to the forefront. I am heartened that you recognize the appalling rise in pediatric AIDS and you see the need for all our citizens and institutions to move past the ignorance and prejudices of past understandings.

For the past two years I have worked in this community to create a trained, compassionate team of nearly 90 pastoral care partners to work one-on-one with those affected by AIDS. These volunteers come from a variety of different walks of life, many different religious perspectives, some are men, some are women, young and old, they are gay and straight, but the one thing that they all have in common is that they care about other people and want to live out their faith perspective.

I could tell you many stories, heart-rending stories, of personal sacrifice by these care partners from the private sector motivated by their own personal faith and their love and their spiritual commitment. I have seen volunteers cancel their own weekend plans to share, instead, camping trips and quiet walks and shopping excursions and even death vigils at the sides of those with AIDS. I have seen our care partners leave long days of work themselves, to head directly to our hospital facilities and stand at the bedsides of dying babies and mothers dying with AIDS. I have seen teenagers give up dates and spend time comforting orphaned babies or aged parents, mourning the loss of their only child.

I believe there is in the ordinary citizenry of our land a wealth of concern for people with AIDS and a willingness to be involved. However, while we are more than eight years into this epidemic, there are still some enormous bottlenecks to the provision of adequate care. Some of these bottlenecks are bureaucratic, some are systemic, and some are institutional. Some of them are merely perceptual, but some are very real. Most, however, are complex because AIDS is complex.

As we have heard it is difficult to determine for several months after birth whether a baby born to an HIV-infected mother carries the virus and most likely will go on to develop the AIDS syndrome. Pediatric AIDS therefore, presents us with some unprecedented moral and ethical conundrums. Should the babies be carried to term to save that percentage which may be reasonably healthy, or should the pregnancies of women with AIDS and HIV infection be terminated to humanely spare such a tortuous death to the sizeable percentage of children who will finally develop AIDS. A thoughtful answer will not be an easy one and there are intelligent people of faith with a variety of viewpoints, even within the Interfaith Networks, of which I am a part. It is not a pro-life or pro-choice issue, it is a question of how we perceive what is most humane for the children. Everyone would prefer that babies not be born with HIV infection in the first place, but the fact is, children and babies are dying from AIDS and they are dying now.

It is incumbent on all of us in both public and private sectors to do more than wring our hands at this mounting crisis. We must begin to act swiftly and effectively, even though the solutions will not be easy.

We must protect the rights of both parents and children with this virus while acting to streamline the processes for adoption and foster care and financing of placement of unwanted and neglected AIDS-infected infants.

The bureaucracies designed for other times and conditions are too lengthy for proper expeditious care of many children with AIDS, or those suspected of ultimately developing the infections.

It is not enough for the religious to merely issue statements about the sanctity of life, or the need for higher moral values; "Faith without works is dead," say the Greek scriptures. There must be a rise in the private sector leadership, including our mainstream religious denominations and organizations, to provide food, clothing, loving foster homes and medical care, amounting to tens of thousands of dollars per child. Otherwise, all the words we say about life's sacredness are empty.

Who is going to act in behalf of life's highest values when AIDS-infected mothers live in squalor and malnutrition and addiction without dignity and without adequate care? Who is going to provide healthy, attractive and life saving alternatives to poor women who see no other options but to sell their own bodies to keep from going hungry? Where are the options when there are no openings, as we have already heard, in the drug rehabilitation programs and when concern over AIDS is last on a teen mother's list of personal priorities? Who can provide the counsel, the direction, the training and the needed jobs? I believe both public and private sectors must work together to provide solutions. And I believe that the religious leaders of our land, if educated and motivated about AIDS, can elicit active financial support and personal involvement from a wide segment of the private sector.

It is true that many religious publications are finally discovering the AIDS crisis and calling for involvement, especially with the so called "innocent victims," (as though adults with AIDS wanted or deserved their fate). However, that involvement needs forthright leadership at the highest levels of our religious institutions, including the willingness to fund homes for mothers with AIDS babies, the willingness to fund adolescent sex education programs, to fund drug rehabilitation programs, to fund pastoral care chaplaincies to persons with AIDS, and the willingness to cooperatively fund and work together with other religious organizations, denominations, secular businesses and private and public institutions which can help slow the spread of AIDS through education, counseling, and rehabilitation.

The specter of death from AIDS has moved well beyond the gay community and the IV drug using community and puts thousands of mothers and children at risk.

Still, we have the curious spectacle of some religious leaders who are not even successfully controlling the sexual behaviors of their own members, but who argue against AIDS prevention education in our schools. It is morally repugnant to deny thorough, clear AIDS prevention education to any of our population simply because we are squeamish about talking explicitly about blood, semen, vaginal fluid, anal, oral and vaginal intercourse, condoms, homosexual, heterosexual and bisexual behaviors. This virus does not care whether we are pro-life or pro-choice, whether we are Black or White, English or Spanish speaking, Catholic, Protestant or Jewish, gay or straight, religious or atheist. The only effective prevention to the rise in pediatric AIDS is a change in sexual behavior and that will come about only with adequate sex education and moral and ethical motivation. If our homes and churches and synagogues can do that job, no time is better than now to prove it.

Let us together, with the support and cooperation of business and government to develop effective and comprehensive education programs, which can include our varying moral precepts, while advancing a full and honest telling of the scientific facts about AIDS.

To that end, the Miami AIDS Interfaith Network with nearly 50 leaders who come from a broad cross section of the religious community is currently planning a First National Conference for Religious Educators and Pastoral Care Givers to develop some common ground on which we can all agree to act in slowing the course of death from AIDS.

Together with the AIDS National Interfaith Network, religious leaders from many different denominations and the many excellent providers of services and care for people with AIDS in this community and nationally, we are working to develop cooperative plans of actions in AIDS education that can even have international impact. But such a conference will not be free. We are still looking for support, both from public and private religious sources, as well as from federal grants.

At a conference on AIDS I attended last year, one participant declared, "the church is a waste to stem the course of this epidemic." I do not believe this has to be true, but I believe it has been true so far. Nonetheless, there are few institutions with more potential for bringing about public openness to discussion and for changing public attitudes than our religious institutions.

Despite all the institutional and governmental reticence to speak out openly on AIDS, I——

Chairman Miller. Reverend, I am going to ask you to summarize your——

Dr. Miller. All right.

Chairman Miller. We are going to run out of time and I want to be sure we get the questions.

Dr. Miller. I bring to mind that it was a man with profound religious convictions, C. Everett Koop, who brought AIDS into the forefront in our national discussion.

I believe that there is a need to offer honest and open incentives for people who give their time and effort from the private sector. I do not think just throwing money at AIDS is necessarily the answer, but I think it does require both public and private sector cooperation.

I think, additionally, there needs to be public support and encouragement to the private sector and particularly to the religious of our land, to put their money where their mouths are about AIDS and about AIDS education. I think the issues of racism and classism and poverty need to be raised in our religious institutions, because I hear more and more from particularly the American Black community, of the reticence to get involved because of perceiving AIDS as simply another burden to the people.

And in closing, I do not believe most Americans want to see a nation where the poor and infirm die in the streets like dogs and where babies are born [illegible] suffer from the racking pain of AIDS infections, and where addicted mothers have as their only goal in life another hit of cocaine.

However, in the face of increasing governmental fiscal austerity, and without a radical involvement of the private sector in provision of increasingly needed services, especially for mothers and children with AIDS, that is the ominous picture in a very short time. In fact, it is already beginning to happen. Our religious institutions can help to change that picture, I believe, but I hope they accept the challenge.

Thank you.

[Prepared statement of Rev. Dr. Roger Miller follows:]

## Prepared Statement of Rev. Dr. Roger P. Miller, Chaplain in AIDS Ministry, the University of Miami/Jackson Memorial Medical Center, Miami, FL

Mr. Chairman, Congressman Lehman, Congressman Bliley, members of this Select Committee, and other distinguished guests: I thank you for the invitation to testify on behalf of some of the weakest and most vulnerable of American citizens, those babies and children infected from birth with the Human Immunodefficiency Virus. As a chairperson of the Miami AIDS Interfaith Network, as the Senior Chaplain in AIDS Ministry here at the University of Miami/Jackson Memorial Medical Center, and as an experienced pastor, educator, and counselor for a number of years, I am delighted that this esteemed body is interested in addressing not only the medical and legal issues of Pediatric AIDS but the ethical, moral, and spiritual issues that this epidemic has brought to the forefront. I am heartened that you recognize the appalling rise in pediatric AIDS and see the need for all our citizenry and institutions to move past the ignorance and prejudices of past understandings and the bureaucratic and political footdragging chronicled so eloquently in the bestseller, **And the Band Played On**, by Randy Shilts.

For the past two years I have worked in this community to create a trained, compassionate team of nearly ninty pastoral care partners to work one-on-one with those affected by AIDS. These volunteers come from many different walks of life, many different religious perspectives, they are men and women, young and old, gay and straight. The one thing they all have in common is that they care about other people and want to live their faith.

I could tell you scores of heart-rending stories of personal sacrifice by these Care Partners from the private sector motivated by their personal faith and love and spiritual commitment. I have seen volunteers cancel their own weekend plans to share, instead, camping trips and quiet walks and shopping excursions and death vigils at the sides of those with AIDS. I have seen our Care Partners leave long days of work to head directly to hospital bedsides of babies and mothers dying with AIDS. I have seen teenagers give up dates to spend time comforting an orphaned baby with AIDS or an aged parent mourning the loss of an only son lost to AIDS.

I believe there is in the ordinary citizenry of our land a wealth of concern for People with AIDS and a willingness to be involved. However, while we are more than eight years into this epidemic, there are still some enormous bottlenecks to the provision of adequate care for persons with AIDS in general and for babies and children with AIDS in particular. Some of these barriers are bureaucratic, some are systemic, and some are institutional. Some of these barriers are merely perceptial but some are real; most are complex, however, because AIDS is complex. The very nature of how HIV is transmitted, detected, and treated means that there can never be simple solutions.

Because it is difficult to determine for several months after birth whether a baby born to an HIV infected mother carries the virus and most likely will die an excruciatingly painful and extended death the issues surrounding Pediatric AIDS present us with some unprecedented moral and ethical conundrums. Should the babies be carried to term to save that percentage which may be reasonably healthy or should the pregnancies of women with AIDS and HIV infection be terminated to humanely spare such a tortuous death to the sizeable percentage which will finally develop AIDS? A thoughtful answer will not be an easy one and there are intelligent people of faith with a variety of viewpoints, even within the Interfaith networks of which I am a part. It is not a pro-life or por-choice issue; it is a question of how we perceive what is most humane for the children. Everyone would prefer that babies not be born with HIV infection in the first place but the fact is: children and babies are dying from AIDS...now! It is incumbent on all of us in both public and private sectors to do more than wring our hands at this mounting crisis. We must begin to act swiftly and effectively even though solutions will not come easy.

We must protect the rights of both parents and children with this virus while acting to streamline the processes for adoption and foster care placement of unwanted and neglected AIDS-infected infants. The beauracracies designed for other times and conditions are too lengthy for proper, expeditious care of many children with AIDS or those suspected of ultimately developing the infection. It is not enough for the religious to merely issue statements about the sanctity of life or the need for higher moral standards; "faith without works is dead" say the Greek Scriptures. There must be a rise in private sector leadership including our mainstream religious denominations and organizations to provide food, clothing, loving foster homes, and medical care amounting to tens of thousands of dollars per child. Otherwise all the words we speak about life's sacredness are empty! Who is going to act in behalf of life's highest values when AIDS-infected mothers live in squalor and malnutrition and addiction without dignity and without adequate care? Who is going to provide healthy, attractive, and life-saving alternatives to poor women who see no other option but selling their own bodies to keep from going hungry? Where are the options when there are no more openings in the drug rehabilitation programs and when concern over AIDS is last on a teen mother's list of personal priorities? Who can provide counsel, direction, training, and needed jobs? I believe both public and private sectors must work together to provide the solutions and I believe that the religious leaders of our land, if educated and motivated about AIDS, can elicit active financial support and personal involvement from a wide segment of the private sector.

At our medical center we have but one paid chaplaincy position for all the persons living and dying with AIDS in our entire system and that position is funded from the secular philanthropic community for only a brief time. Where are the responsible religious bodies which can work cooperatively to meet the need for specialized psychosocial, emotional, and spiritual care for People with AIDS?

It is true that many religious publications are finally discovering the AIDS crisis and calling for involvement -- especially with the so called "innocent victims" (as though adults with AIDS wanted or deserved their fate!) However, that involvement needs forthright leadership at the highest levels of our religious institutions including the willingness to fund homes for mothers with AIDS babies, the willingness to fund adolescent sex education programs, the willingness to fund drug rehabilitation programs, the willingness to fund pastoral care chaplaincies for Persons with AIDS, and the willingness to cooperatively fund and work together with other religious organizations, denominations, secular businesses, and private and public institutions which can help slow the spread of AIDS through education, counseling, and rehabilitation.

The spectre of death from AIDS has moved well beyond the gay community and the IV drug using community and puts thousands of mothers and children at risk. Still we have the curious spectacle of some religious leaders who aren't even successfully controling the sexual behaviors of their own members but who argue against AIDS prevention education in our schools. It is morally repugnant to deny thorough, clear AIDS prevention education to any segment of our population simply because we are squeamish about talking explicitly about blood, semen, vaginal fluid, anal, oral, and vaginal intercourse, condoms, and homosexual, heterosexual, and bisexual behaviors. This virus does not care whether we are pro-life or pro-choice, black or white, English or Spanish speaking, Catholic, Protestant, or Jewish, gay or straight, religious or atheist. The only effective prevention to the rise in Pediatric AIDS is a change in sexual behavior -- and that will come about only with adequate sex education and moral and ethical motivation. If our homes and churches and synagogues can do the job no time is better than now to prove it! Let us get together with the support and cooperation of business and government to develop effective and comprehensive education programs which can include our varying moral precepts while advancing a full and honest telling of the scientific facts about AIDS.

To that end the Miami AIDS Interfaith Network with nearly 50 leaders who come from a broad cross section of the religious community is currently planning a First National Conference for Religious Educators and Pastoral Care Givers to develop common ground on which we can all agree to act in slowing the rise of death from AIDS. Together with the AIDS National Interfaith Network, religious educators from many different denominations, and the many excellent providers of services and care for People with AIDS in this community and nationally we are working to develop cooperative plans of action and AIDS education that can have international impact. But such a conference will not be free. We are still looking for support both from private and religious sources and from federal grants.

At a conference on AIDS I attended last year one participant declared, "The church is a waste to stem the course of this epidemic." I do not believe that has to be true but I do believe it has been true so far. Nonetheless, there are few institutions with more potential for bringing about a public openness to discussion and for changing public attitudes than our religious institutions. Despite all the institutional and governmental reticence to speak out openly on AIDS I remind you that it was a man with profound religious convictions who most influenced our country to bring AIDS into wide public discussion. That man is the illustrious Surgeon General C. Everett Koop.

I believe that in the private sector there are thousands of points of light in the dark picture of AIDS that hovers over our world. There are thousands of caring individual Americans who make up this nation's religious, business, industrial, and political institutions and who are willing to take their place along side of (but not in place of) those organizations and institutions already working to slow the increase in Pediatric AIDS. Why can't government and religion work cooperatively to motivate this private sector to more personal involvement as well as to provide concrete incentives to encourage this involvement? What about tax incentives for those who give their time and money to provide help for Persons Living with AIDS and their children? What about creating food pantries, clothing banks, recreational facilities, respite care to mothers needing a few hours of relief, church and synagogue based nursing care, and volunteer support services as a part of our faith communities' outreach and mission programs? How about easier tax deductable credits for the givers?

Some people feel that the answer to every problem is to throw money at it. Others believe that less government will produce more individual responsibility. The truth probably lies somewhere in between both extremes. We greatly need increased national funding for AIDS research, treatment, and prevention, but we also need a greatly expanded private sector involvement of our business, industrial, and religious institutions. Instead of permitting our differences to keep us from effective action let them spur us to new models of cooperation between private and public sectors.

Every church and synagogue in our nation ought to already be learning about AIDS, talking about AIDS, and opening their doors without blame, accusation, or judgment to those who are suffering from this plague. There ought to be throughout our faith communities support groups and care facilities for anyone with HIV infection, and our religious institutions ought to be in the forefront of raising money for medical care, medical research, AIDS education, and for personal care of all kinds of persons living with AIDS. True spirituality requires responses to both children and adults that are based on understanding rather than fear, mutual concern rather than personal greed, and tolerance rather than bigotry.

Nowhere is the institution of racism and classism in America more apparent than in the way churches (expecially minority churches) are dealing with AIDS. It is no accident that AIDS is ravaging the poorer Black and Hispanic and Carribean immigrant communities while little is being said from the pulpits of those cultures except an occasional perjorative pronouncement against "perversion". Out of all the trained Care Partners in our AIDS ministry only one is a Black American! In the Miami AIDS Interfaith Network only two are American Blacks when between thirty and fifty percent of our medical center's inpatients with AIDS or HIV infection are Black. Is this because AIDS is seen by the poor as yet another of many problems over which they have no power or control? Now that discrimination against people of color is legally unacceptable what is the responsibility of our religious institutions to educate and empower those on the bottom of the economic ladder?

I do not believe most Americans want to see a nation where the poor and infirm die in the streets like dogs, where babies are born to suffer from the racking pain of AIDS infections and where addicted mothers have as their only goal in life another hit of cocaine. However, in the face of increasing governmental fiscal austerity and without a radical involvement of the private sector in provision of increasingly needed services, especially for mothers and children with AIDS, that is the ominous picture in a very short time. In fact, it is already beginning to happen. Our religious institutions can help to change that picture, I believe. I hope they accept the challenge!

Chairman **Miller**. Thank you. Thank you very much for your testimony. Mr. Plummer, some years ago, this committee, at the insistence of Congressman Lehman, came to Jackson Memorial Hospital and the Mailman Center and between the two institutions we spent quite a bit of time discussing the cost of low birth weight babies. And I think we set out a course for this committee, and eventually for the Congress, that culminated this year with the participation of my two colleagues here in the largest increase in the Women, Infants and Children's funding in the last 10 years of that program. WIC provides prenatal care and nutrition assistance to try to stem the cost of low birth weight babies in recognizing that the cost of prevention and intervention is cheaper than dealing with the results. It also, of course, improves the health of the child and the mother.

You are presenting us again today a chart of the awesome fiscal impact of AIDS on institutions, setting aside for the moment the human suffering and misery and concern that we all have. We can spend an awful lot of money on prevention before we get to these kinds of numbers. These figures are not, if I look at them correctly, are not out of balance with what we are starting to relay presented to us from other institutions and the costs that they are starting to relate to the Select Committee. Who is paying the bill? Are these all covered?

Mr. **Plummer**. I think that for the most part the Federal and State Governments are paying the bill. We do have portion of our population with AIDS who are not covered. Jackson Memorial Hospital alone, despite the fact that we have almost $10 million coming into our community to help, to defray some of the costs of caring for AIDS, Jackson Memorial Hospital alone had almost a $5 million deficit this past year, fiscal year, in caring for persons with AIDS.

Chairman **Miller**. You mean just caring for individuals with AIDS?

Mr. **Plummer**. AIDS and——

Chairman **Miller**. What do you project in terms of the future?

Mr. **Plummer**. That as we deal with larger and larger numbers that cost is just going to continue to escalate.

Chairman **Miller**. How long can this institution stand that?

Mr. **Plummer**. It cannot stand it any longer. We have got to look at providing the dollars to take care of this patient population. But I think that, again, the cost of care in terms of hospitalization can be continued to be minimized, as we look at more and more prevention, education and early intervention. We are going to see more and more medications that are going to provide us with the opportunity to provide early intervention, and we have got to begin to shift the dollars that we have available to us, to this early intervention, so that the cost of care for hospitalization can be reduced.

Chairman **Miller**. Dr. Laureano-Vega, let me ask you something. In the earlier testimony and in written testimony received by the committee in conjunction with this hearing, there is the constant suggestion that, if I am stating it right, within the male population there is a very very difficult task in getting individuals to change behavior in the Hispanic community and in the Black community—even when, according to some studies, they know in fact they are endangering themselves, or possibly endangering somebody else or infecting somebody else. It was suggested in one of the testimonies that they are more aware of it—they are still taking risks but they are worrying more about it. But the risk taking activity is still being engaged in, in this case whether it is drug use or sexual relations with somebody else once you are infected or risk being infected. You described a number of things that the League is attempting to do. Where are we in terms of being effective in the Hispanic community, the Haitian community, and in the Black community?

Dr. **Laureano-Vega**. We are just getting started and the epidemic has been around for 10 years, that is where we are. Mainly because there are not sufficient monies to put into education and prevention, so that programs can be expanded in terms of manpower alone. We have been trying to get our community to stop smoking for the last 20 years also. Behavior change is one of the most difficult things to accomplish for a human being, especially for human beings that live in such a free society as the one we have.

So, it is very important to target and to, unfortunately it all costs money. We need to let go of buying a couple of bombers and then put some more money into education and prevention programs that target adolescents, that target specifically younger males of minority origin, older males of minority origin. We have to put together programs which really look into the idiosyncracies of each one of our subcultures, so we can appropriately target them.

Chairman **Miller**. You know, we have had some experience in the gay community, in some of our cities where they have been able to put together two amazing projects. One is a very considerable support network for people with AIDS, and the other is a network attempting to get people to change their behavior, to change the risks. And, we have watched the numbers of AIDS cases in the gay community, certainly in my State of California, decrease substantially from the escalation that was taking place. What is our ability, do you think, even if it is speculative, in terms of putting together that kind of open and public support networks in the hispanic community and the Haitian community, with respect to this problem?

Dr. **Laureano-Vega**. I think it is very possible. One of the main differences that I see is the fact that, of course, the gay community rallied and supported economically the institutions which were actively pursuing the decrease of the incidents of HIV infection within the gay community. We have not seen that yet in our community, because our communities still have not taken responsibility for the problem that they have with regard to this epidemic.

One of the things that we need to do is make them realize that there is a responsibility towards ourselves as a community and we have to take it seriously; that the problems that face our community in this epidemic are, in some cases, very similar to those faced by the gay community and in some cases very different from those faced in the gay community.

Chairman **Miller**. Let me ask you this. Do you expect it to be more difficult, or just different? I mean, your testimony suggests you expect it to be more difficult, but I do not know if I am reading it right.

Dr. **Laureano-Vega**. We are faced with very difficult issues. We are faced, for example, with issues of people that do not want to come forward and say that they are HIV positive, even though they already found out, because Immigration had them tested so that they could get their residency. And they are hiding, they will go right out and hide. One, well this is what we have been stating all along, that if you go out and you test people and it is not kept anonymous, that people are going to go into hiding, people are going to go underground. There are thousands of Hispanics and Haitians that are testing positive and they are hiding. They are not seeking appropriate help. We have a very small amount.

Chairman **Miller**. When you say they are hiding, we can assume from this side that, whatever activities they were engaged in, they are just continuing to engage in, because if they are hiding they are not receiving counseling, they are not receiving any kind of educational effort?

Dr. **Laureano-Vega**. That is right.

Chairman **Miller**. Okay.

Dr. **Laureano-Vega**. Particularly because of the way the whole system has been set up. It is a prime example of doing things the wrong way. There was no counseling instituted whatsoever with this testing. People went out and they found out by mail, you are not going to get your residency because you are HIV positive, and then these are individuals that have maybe been in this country maybe 10 or 15 years, they probably became infected in this country. And at this point they are being denied residency after they had trusted the Government enough to come out and fill out their paperwork and do everything the right way. And they are just being told sorry Charlie, the next possible alternative for us is deportation for you. And at that point then what are we doing, we are exporting infected people to countries which do not have a health care system and a prevention and education system which is as sophisticated as ours. We are exporting people that are infected to countries where there is already a problem, we are just increasing it for them. We are also knocking out for these individuals possibly the only alternative for adequate treatment and possible cure that there is in the world, because most definitely in the Third World country they are not going to get the adequate care that they need.

Chairman **Miller**. Thank you. Congressman Lehman?

Mr. **Lehman**. Thank you. Dr. Miller, on the second to the last paragraph of your second page, you say that many religious publications have finally discovered the AIDS crisis and calling for involvement, especially with the so-called innocent victims, as though adults with AIDS wanted or deserved their fate. And then you say, what the involvement needs is forthright willingness to fund homes, willingness to fund pastoral care, willingness to do this, willingness to do that. Is this an indictment of the religious community? Are you saying the religious community is copping out of the AIDS crisis?

Dr. **Miller**. I think the religious community is in a very high state of denial. They are in a denial.

Mr. **Lehman**. In other words, a cop out.

Dr. **Miller**. Absolutely.

Mr. LEHMAN. Right. Question answered. Next question. Dr. Laureano-Vega. On page, "By and large the Hispanic physicians have been essentially quiet during this crisis and only a few have become spokespersons or advocates at a time when they need most to be heard in order to save lives." Are the Hispanic physicians less forthcoming than the other positions in that community?

Dr. LAUREANO-VEGA. I would tend to say that this is something that has happened universally across all communities.

Mr. LEHMAN. I did not ask you all communities. I said are the Hispanic community——

Dr. LAUREANO-VEGA. I think the Hispanic physician has not come forward.

Mr. LEHMAN. May I ask you the same question then, do you think the Hispanic medical community is copping out on the AIDS crisis?

Dr. LAUREANO-VEGA. Yes.

Mr. LEHMAN. Thank you.

Chairman MILLER. Congressman Durbin.

Mr. DURBIN. I hope that Congressman Lehman does not ask us about the Congress.

Mr. LEHMAN. The answer is yes.

Mr. DURBIN. I will say in our defense that on the Budget Committee we have each year increased the request of the administration for funding in this area, not only for medical research, but also for all related activities which have been so duly noted this morning. There is more to do, much much more to do.

I find it interesting, I listened to the problems which present themselves here in Miami, Florida and think of my own Central Illinois Congressional District, which is a much different world in many respects, but also very similar. And the one thing that I find very curious in my concern about the issue of infant mortality in some of my communities, is the role of religious leaders. And Dr. Miller, Dr. Laureano-Vega, Dr. Tribie, I think, have highlighted this.

Let me start off by saying. Dr. Laureano-Vega, do you believe that the Haitian and Hispanic religious leaders can have some influence on the people whom you are trying to serve?

Dr. LAUREANO-VEGA. Yes. Our community, as I said before, is influenced by our leaders. Our leaders are credible leaders, are politicians, health care providers and the religious leaders among others. If they were to stand up and state that we need to behave and we need to think along very specific lines, because the epidemic warrants us to be more rational rather than emotional, I think that they would be a very very big influence in terms of helping curtail the epidemic and change the attitudes of the community so that the epidemic can be dealt with in a better fashion.

Mr. DURBIN. Dr. Miller, in the closing page of your testimony, which unfortunately because of our time constraints you could not read. In your second to last paragraph, is a very eloquent and I think forceful indictment of religious leaders. And I might say it is not unique to South Florida, it is unfortunately a difficult task for many of them to rationalize and to accept their responsibility.

You testified earlier about your attendance at so many conferences can we hope that maybe as an outgrowth of this hearing, we could have some sort of Miami meeting of religious leaders? Is there a Black Ministerial Alliance, is there a Hispanic Ministerial Alliance, is there a Haitian Ministerial Alliance which could now as a result of this hearing and the fact that our friends in the media may publicize it, come together and finally deal with this candidly about their important role in this? Is that too much to expect?

Dr. **Miller**. That is one of my strongest desires that out of this hearing can come that kind of support, that we can give permission and say it is okay for eminent religious leaders in our community and in our nation to speak forthrightly and up front about AIDS. And it does not brand them with any kind of stigma, which heretofore, everyone has been hanging back for fear somebody would think that they might have some kind of other agenda. And it concerns us all.

Mr. **Durbin**. Well, simply as a visitor to your community, and I guess I am far enough away from home to be considered an expert, I would hope that that does happen, because I think it is important to develop culturally and from a medical viewpoint that we have that kind of discussions and perhaps again, my friends in the media here today will seize this opportunity to then ask leaders in each of these sectors what they think of such a conference, it might then occur.

And let me conclude by saying, as I started off, I do not want to get the politicians off the hook either. We have a lot of responsibility for more candor, more cooperation and a greater effort to understand the deficit of this problem. And I hope again that this hearing will be a catalyst for the local, state and Federal leaders in this area to get together and to engage in that same dialogue. Thank you.

Chairman **Miller**. If I might ask a question. Dr. Tribie, where are we in terms of, I guess the term is culturally appropriate materials and approaches to this problem, and I would use the term culturally appropriate to refer to adolescents and/or the Hispanic/Haitian/Black community what have you. In your work with the League and your attempt to go out and to reach these various populations, what are the resources available to you? I am not talking about money, and that may be the basis which you do not have it, but are we developing materials that we can take to the community? Are we upgrading the training of individuals who can then go to this community and talk with the patients on a basis in which the individuals would be welcome and would be understood? Is that happening, or are we still talking about our inability to do it?

Dr. **Tribie**. Both. I think materials are really not readily available, mostly talking for if we might go into the Haitian community. There is maybe one or two videos available for the past 10 years. One is very, very culturally appropriate, but again, it was created in New York for the large segment of the Haitian population there. I would say no, we are not really creating relevant materials for the Haitian community, but I think there is a movement where more people who have been in the battlefield, I would say, for the past three or four years and know the issues and how to target the communities, they are getting together and try to create more relevant.

Chairman Miller. But you know, there are a number of points at which different communities come in contact with governmental agencies. And I do not know all of the Florida laws and whether you can counsel people about abortion, or options to pregnancy or sexual activity. I do not know the extent to which schools can undertake this kind of discussion about sexual activities and the responsibilities of young men and women. But, you know, we seem to have all of these points where young people and others come into contact with governmental services. The question I am starting to wonder about here is, are we doing anything to see that those points of contact are more sensitive, more understanding and better able to convey the information? We keep talking about talking to all of the children in schools, but I do not know that anybody is upgrading the ability of a teacher to discuss this subject matter, or a physician, or a social work, or a WIC director, or a nutrition field worker. You know, I do not know that we are making this kind of effort. It seems to me that when I look at most of the successful social service delivery systems, if you will, a lot of the credit goes to the skill of the person delivering the message. And I just do not know if this is going on in AIDS.

Dr. Tribie. In my community, though, it is basically verbally the one on one intervention, because of the high literacy problem we have. I am always against printed brochures, it is a nice gesture for my people, but are they really going to understand anything? So, I do not believe so much in written materials and pamphlets. I do believe in letting the message out verbally, radio, which is a very good media way of reaching my people. The video they just produced in New York, this is definitely something that is appropriate, because they can watch it, it is entertaining and also the information is being passed. Also with the Haitians you have to relay the message in a very, not carry away, it has to be interesting, it has to be funny, at the same time serious, you are going to get the message across. And they have done a beautiful job in New York, I wish in Florida, in Miami we could create something to compliment whatever they have done there.

Chairman Miller. What is standing in the way of that?

Dr. Tribie. I guess resources would be the only answer, because we certainly have the professionals. I am in the Haitian community and I am targeting, there is this group which is a theatre group and they are very knowledgeable about the AIDS issue and they are willing to come forward and do something, but everybody says yes, but then where do we go from there. The Health Department also is working with us and I am sure we could all get together, but I guess resources basically is the thing.

Dr. Laureano-Vega. I would like to add onto that. For example, educational processes in the Haitian community are going on with respect to yes, there have been training programs put together for the Haitian Medical Association in attempt to educate the Haitian Medical Association so they can better propagate the information, both on radio programs and when they are talking to their client when they are coming into their offices.

We had, the League, has established for example a women's project which is trying to raise awareness within the community of women that are Haitian that are child bearing, of very specifically targeting for example of beauty parlors and day care centers and giving the information to just the lay person and then that way the information can be disseminated in the community by a way of antidotal and just conversation.

We have, for example, participated in the training of AIDS resource teachers with the Dade County Public School System, in which we have educated one person which is a base coordinator in each one of the schools in this county. We have also participated in a 30-hour-long comprehensive AIDS education program for Dade County Public School System teachers, in an attempt to bring them up on both scientific and cultural issues, so that they can better deliver the AIDS curriculum to 6th, 7th, 9th, 10th graders. We have participated with the Dade County Public School System in upgrading the curriculum, making sure that it is medically and scientifically accurate and that the methods used in the curriculum are good in terms of disseminating the information to the children in our area.

Chairman **MILLER**. That is encouraging.

Dr. **LAUREANO-VEGA**. So there are many things we are participating in to get the resources that are needed, training individuals so that they become resourceful with regards to AIDS for the community, but we are working with a very very limited resources. My agency's budget is less than $200,000, a year, and the amount of work which comes out of the agency with regard to public health and prevention in the community and direct client service and taking care of people with AIDS and instituting educational programs for people with AIDS, is a lot. And it is overwhelming, and we need more people, we need more resources.

Mr. **LEHMAN**. Did you get your money from United Way, did you get your money from HRS?

Dr. **LAUREANO-VEGA**. Yes we do, we receive money—no not from the United Way because you need to be affiliated with the United Way for, I believe two years, before you can get any money coming in. I intend to apply for some money from the Resource Pool this year and I hope they find my application to be good.

But for example, I will give you an example.

Mr. **LEHMAN**. How about have you considered a demonstration project, maybe with Federal funds.

Dr. **LAUREANO-VEGA**. We have monies from the U.S. Conference of Mayors, who are funded through the Office of Minority Health in Washington D.C. We have a contract with the State of Florida. We have contracts with South Florida Networks, with the State of Florida. We just applied for a C.D.C. grant, for $215,000 and because of inappropriate money allocations we were not funded. We were approved, but not funded. The reason why we were not funded, because they ran out of money before they got to us. So there is a lot of connotations to that.

Mr. **LEHMAN**. We will try to send some money from the B-2 bomber.

Dr. **TRIBIE**. Right.

Mr. **LEHMAN**. We will work with you.

Mr. **PLUMMER**. I think in response to your question, I think that we are beginning to see more and more educational to the health care provider, but it not happening fast enough. The population is growing more rapidly than we are able to keep up with the need in terms of educating, not only physicians and nurses, but teachers, other people that interface and will be affected in dealing with the problem.

Chairman MILLER. Let me ask, is there a program that makes an effort to take whatever number of young people, it might be high school students, and work with them? Conceivably we can use the summertime. Even if you paid young people to come to the program to educate them, if you educated 2, 3, 4 percent of the population, if you selected out school leaders and young people that had some multiplier impact in their schools, that there would be a possibility of starting to build that anecdotal knowledge.

Dr. LAUREANO-VEGA. I do not know who is going to receive testimony from the Dade County Public School AIDS Education Information Office, but she may later on if she will provide testimony, tell you that yes she is the Director of that program; she is in the process of creating active programs of peer teaching and in taking in students and even putting together a prospective teenage hotline to the Dade County Public School System and private school teenagers who may want to call into that hotline and receive information from their own peers. Peer education is very important. Concepts that are just beginning to be developed in this area, but they are being put in place.

Chairman MILLER. We have seen that this kind of peer counseling is important, and, with respect to other problems, the dissemination of information seems to be very successful in different communities.

Any further questions? Well, thank you very much for your testimony. Let me say to those who have been in the audience that the formal record of the committee will be held open for a two week period of time so that if people want to send us additional information we would certainly welcome it, or if people have comments on what members of the various panels have said, either that you agree or disagree with, we would also welcome that information. And with that, let me again thank Congressman Lehman and Congressman Durbin for joining us here today. And Congressman Lehman for his invitation to come to South Florida to look at this problem and again the support of Jackson Memorial and Mailman Center for this hearing.

With that, the committee will stand adjourned. Thank you.

[Whereupon, at 12:45 p.m., the committee was adjourned.]

[Material submitted for inclusion in the record follows:]

## OPENING STATEMENT OF HON. THOMAS J. BLILEY, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF VIRGINIA, AND RANKING REPUBLICAN MEMBER

By 1991, as many as 20,000 children will become HIV-infected, and 3,000 will have contracted AIDS. AIDS is now the ninth leading cause of death among children 1 to 4 years of age. If present trends continue, it could be among the top 5 causes of childhood death within the next 3 to 4 years. The current rise in the incidence of pediatric AIDS presents us with an important public health challenge. Nowhere in the country is this better understood than here in Florida, where the cumulative number of pediatric AIDS cases is the second highest in the nation. If we are to meet this challenge, we must recognize four components of the overall problem.

First, we cannot dissociate the pediatric AIDS problem from the drug problem. Approximately 70 percent of perinatal AIDS cases are related to IV drug usage by at least one of the child's parents. In over half of the cases, the mother herself was the user. Nowhere is the horror of drugs more manifest than in this issue: some mothers around this nation are injecting themselves and their unborn children with drugs and at the same time putting them at high risk for contracting AIDS. We have to keep in mind that any anti-pediatric AIDS strategy must also be an anti-drug strategy. If behavior is not changed, the Age of AIDS will be a long and destructive one.

Second, we need to recognize the potential increase in demand for foster care generated by pediatric AIDS cases. Almost a third of infants born with AIDS will not be cared for by their biological parents. Finding adequate foster care is often difficult. As one might imagine, many prospective parents are reluctant to accept an HIV-positive child. Compounding the problem is the fact that 90% of HIV-positive infants and children exhibit some form of neurological dysfunction or developmental disability. Moreover, many HIV-positive children are minorities, who have been harder to place. With those obstacles, finding foster care can be extremely difficult. Because of that, we need to offer as much help as we can to the compassionate families who decide to take these children into their homes.

Third, we need to continue research efforts in this area. HIV-infected mothers do not necessarily transmit the infection to their infants. Only about 25%–50% of infants born to HIV-infected mothers become infected themselves. Right now, we don't know exactly how the infection is transferred from mother to infant in the womb. If we find out, it may be possible to discover a method to block the transference. We need to continue research to find out if the potential truly exists.

Finally, and most importantly, we need to testify to the role which religious and private-sector institutions must play to comfort the sick and prevent the continued spread of this disease. When we should be doing everything we can to welcome private-sector involvement and assistance, it is often the case that there is little public/private cooperation; sometimes, private-sector help is actually discouraged. With an issue as important as this, we need as much of a cooperative effort as possible.

Throughout the public debate on AIDS, some educators and health professionals have offered some radical ideas in the face of successful public health measures. They have clung to the belief that knowledge, in place of neglected character, can lead to logical conclusions. By doing so, they defy numerous studies which demonstrate that knowledge alone does not change behavior. Now, as pediatric AIDS gains attention, there are disturbing rumblings about abortion and sterilization as "solutions". But such social insurrectionists have confused the power of government and medicine, whose powers are severely limited, with character and social morality.

HIV infection in newborns and children is at the vortex of many public policy issues. It is one of those issues which periodically rises to require an examination of our national conscience—what is America about? Our actions will forever be measured against Jefferson's simple question: "Sometimes it is said that man can not be trusted with the government of himself. Can he, then, be trusted with the government of others?"

Therein lies our conflict of today. By asserting an unlimited right to privacy over the past 20 years, we have witnessed the self-destructiveness of man. Like scum on a pond, drug abuse, deviant sexual activity, abortion, and pornography have risen to foul our nation's health. Such activities have been excused and defended as exercises in personal liberty. These claims are self-deluding. Our right to privacy is grounded in and therefore must be consistent with natural law. One who professes a belief in liberty but who acts in contradiction of natural law is engaging in hypocrisy.

The future of AIDS is America's future. How will we, as a people, assure care for the suffering, halt the spread of a deadly disease, and protect the public health?

As public officials and community leaders, we must give to young people the necessary encouragement to avoid tragic consequences. HIV infection is 100 percent preventable; that is the important hope we can offer. Yet, we know that our youth are tempted by the fantasy of short-lived sexual relationships without commitment and the fraudulent promises of drugs. We know that these are mirages which lure them into indifference, self-isolation, and even violence against themselves and others. Thus, we must help our young people build the skills required to assume the responsibilities which go with being a free people. These skills certainly do not rely solely on formal education, they include attitudes and knowledge gathered from television, magazines, and the daily lessons of life. We may say it in different ways, but the idea is the same—our form of government depends on the individual governing himself. This is an old theme, but it is not an old-fashioned one. The indissoluble union between rights and responsibilities must be taught and reinforced.

Human life is of divine origin. With this knowledge, we affirm the full value of each member of society as unique and irreplaceable. If the value of life is lessened because of disease, infirmity, or dependence, then at some point in our lives we are all at risk. Government does not grant us the right to life, it can only protect it.

This is one of the obligations we must all take up. AIDS is not just about death for those who suffer it; it is about the unshakable value of life which we profess. AIDS is a test of faith, not just of others, but of our own. Will we allow the babies to live their short lives only in hospital nurseries? Will we abandon the sick to a sense of uselessness in suffering? Will we not show that love is more powerful than anger, bitterness, and contempt? Will we abandon our vulnerable to the drug vultures who will consume the last vestiges of their victims' dignity? If we reject these children, will we not be treated likewise?

We can embrace the person but denounce the act. We need to show that sacramental commitment to marriage holds greater rewards than the dehumanizing relationships our young people are experiencing today. We must reach out to those who suffer in conscience as well as body. We must, at the same time be clear, direct, and unambiguous about the risks of certain behavior. And we must persevere in teaching it, not in judgment but in solicitous care.

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August 4, 1989

# AIDS AND YOUNG CHILDREN IN SOUTH FLORIDA

## Minority Fact Sheet

CONTENTS

Background........................................p. 1
Incidence of Pediatric AIDS.......................p. 1
Foster Care.......................................p. 2
Federal Programs..................................p. 3
Florida and Dade County...........................p. 4
Mailman Center....................................p. 5

Prepared by Scott Bailey

## General Background

- Ninety percent of infants and children with HIV infection exhibit some form of neurological dysfunction or developmental disability. [Carolyn Doppelt Gray, Commissioner, Administration on Developmental Disabilities, OHDS, testimony before the Committee on Government Operations, 23 February 1989.]

- The drug AZT is the only drug approved for the treatment of AIDS, but it is licensed for adult use only. That may soon change. The drug has been used on children experimentally, and the Phase I safety trials have been completed. The Phase II safety and efficacy trials are now being done. [CRS IB 89099]

- Most children with AIDS were infected by their mothers. Eighty percent of children contract AIDS through their mothers; 18% contract it through transfusion of contaminated blood; in the remaining 2%, the transmission route is uncertain. [Ibid.]

- Of all women who transmit AIDS to their children, most mothers contracted AIDS through IV drug use (52%) or through sex with an IV drug user (20%). [Centers for Disease Control, "HIV\AIDS Surveillance," July 1989.]

- HIV-infected mothers do not necessarily transmit the infection to their infants. Only about 25%-50% of infants born to HIV-infected mothers become infected themselves. [*Final Report of the Secretary's Work Group on Pediatric HIV Infection and Disease*, DHHS, 18 November 1988.]

- Children with AIDS do not survive long. Once diagnosed with AIDS, the mean length of survival is 14 months for those infants infected perinatally, and 28 months for those infected through blood transfusion. [Ibid.]

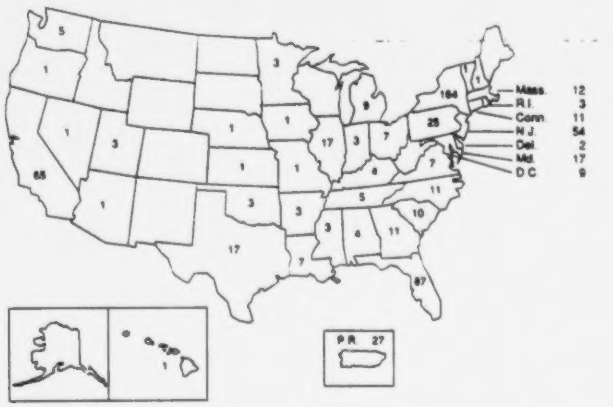
## Numbers and Rates of Pediatric AIDS

- AIDS is now the ninth leading cause of death among children 1 to 4 years old. If present trends continue, it could be among the top 5 causes of childhood death within the next 3 to 4 years. [*Final Report of the Secretary's Work Group on Pediatric HIV Infection and Disease*, DHHS, 18 November 1988.]

- The Public Health Service predicts that by 1991, as many as 20,000 children will become HIV-infected, and 3000 will have contracted AIDS. [cited in GAO, *Pediatric AIDS: Health and Social Service Needs of Infants and Children*, May 1989.]

- Children affected with AIDS represent 1.6% of total AIDS cases. [cited in CRS IB 89009, 16 June 1989.]

**Pediatric AIDS cases, reported July 1988 through June 1989, United States**



Source: HIV/AIDS Surveillance, CDC, July 1989.

- o As of July 1989, there have been a cumulative total of 1,681 cases of pediatric AIDS reported. In the 12 month period from July 1988 through June 1989, 620 cases were reported. [Centers for Disease Control, "HIV\AIDS Surveillance," July 1989.]
- o CDC statistics do not include children infected with HIV but who are asymptomatic or have only early symptoms of infection. Most experts believe that for every child with AIDS, there are 2-3 who are HIV-infected; some put the number as high as 10. [GAO op. cit. & IB 89009]

**Foster Care**

- o Approximately 25% to 33% of infants born with AIDS will not be cared for by their biological parents. [Tourse and Gundersen, "Adopting and Fostering Children with AIDS," Children Today, May/June 1988]
- o Confidentiality can at times pose problems. In Massachusetts, for example, the laws surrounding confidentiality are such that social workers have

occasionally found themselves in the position of not being able to tell a substitute parent that an adoptive or foster child is at risk for AIDS.

- The Florida foster care system has strict confidentiality policies -- e.g. children's HIV status is never written on their records. The State does, however, dictate that certain people must be told about children who have AIDS, ARC, or are HIV positive: 1) the counselor handling the case, 2) the child's medical practitioner, and 3) the foster care provider who has agreed to accept the child for placement. [State of Florida, "Guidelines for Placing HIV Positive Children in Emergency Shelter and Foster Care," 28 February 1989.]

**Federal Programs for HIV-Infected Children**

### Federal Funding Targeted to Pediatric AIDS

(in thousands)

| | FY86 Actual | FY87 Actual | FY88 Actual | FY89 Est. | FY90 Est. |
|---|---|---|---|---|---|
| NIH | $4,650 | $11,289 | $37,270 | $50,343 | $65,981 |
| ADAMHA | 229 | 5,084 | 7,246 | 8,250 | 9,200 |
| CDC | -- | 3,900 | 19,629 | 26,548 | 33,475 |
| HRSA | -- | -- | 4,480 | 7,904 | 7,904 |
| OHDS | -- | -- | 2,795 | 2,795 | 2,795 |
| Total | $4,879 | $20,273 | $71,420 | $95,840 | $119,355 |

Source: Agency Budget Offices, compiled by CRS, 2/89

- The National Institute of Health funds are predominantly used for research on how to block transmission of AIDS from mother to child, how to treat disease manifestations in children, and how best to screen and diagnosis HIV positive children. The funding for the Alcohol, Drug Abuse, and Mental Health Administration is used for programs to reduce the number of IV drug using mothers. Centers for Disease Control funds are used for epidemiological studies. Funds under the Health Resources and Services Administration and the Office of Human Development Services are used for a broad array of education and treatment projects.

- In addition to funding directly targeted to pediatric AIDS, there are general programs which benefit HIV-infected children. Medicaid is probably the most important of these programs, since many of AIDS-afflicted children are poor and qualify for Medicaid. Furthermore, Medicaid Home and Community-Based Services Waivers have allowed States to expand Medicaid eligibility and the range of allowable services. The waivers can be used to provide targeted health care and related services -- such as case management, home care, and nursing -- to persons with AIDS or AIDS-Related Complex (ARC). The Medicare Catastrophic Coverage Act (PL 100-360) expanded the authority and targeted children under 5 years old who are or will be placed in foster or adoptive homes. Medicaid funding figures for pediatric AIDS are not available, but Medicaid spending for all AIDS purposes was $330,000,000 in 1988 (Federal share). [GAO, Pediatric AIDS, op. cit. & William Winkenwerder, "Federal Spending for Illness Caused by the Human Immunodeficiency Virus," New England Journal of Medicine, 15 June 1989]

- Another source of indirect funding is Title IV-E of the Social Security Act authorizes funds for foster care for children eligible for AFDC. The Federal government provides matching funds to States for maintenance and administrative costs of foster care. Foster care children with special needs, such as children with AIDS are usually given higher reimbursement rates.

## Florida and Dade County Background

- Approximately 1 in 200 women bearing live children in Florida in 1989, may be infected with HIV. [State of Florida Department of Health and Rehabilitative Services, "Preliminary Findings: HIV Seroprevalence in Women," December 1988.]
- Florida ranks second in the nation behind New York in number of cumulative pediatric AIDS cases. New York has 500, and Miami has 215. [Centers for Disease Control, op. it.]
- Blacks are overrepresented in pediatric AIDS cases in Florida. Black infants are 6 times more likely to be victims of pediatric AIDS: 80% of pediatric cares in Florida are black, while only 13% are white. Hispanics represent 7% of cases. [Department of Health and Rehabilitative Services HIV Seroprevalence Study, State of Florida, 31 March 1989.]
- Most children in Florida receive AIDS from a parent. Eighty-five percent contracted AIDS through their mothers; 5% through transfusion; 3% developed it through hemophilia; and 7% contracted it through other means. [Ibid.]
- Dade County accounts for almost half (49%) of all pediatric AIDS cases in Florida. [Ibid.]
- Among metropolitan areas of residence, Miami ranks 2nd in cumulative number of pediatric AIDS cases. Miami had 100 as of July 1989. [Centers for Disease Control, op. it.]

## Mailman Center

The University of Miami Mailman center for Child Development is a not-for-profit institution which has been active for 20 years. Financial support comes primarily from the University and from grants from Federal and State government, as well as from private philanthropy. The Center serves developmentally disabled children from Dade County, Florida and the Caribbean. The Mailman's programs provide diagnostic services and care for children with developmental problems in an inter-disciplinary clinical setting. The interdisciplinary teams are made up of specialists such as psychologists, social workers, pediatricians, speech pathologists, nutritionists, nurses, physical therapists, and geneticists. Each year, the Center's staff sees more than 6,000 children and their families in addition to 2,500 adults for genetic testing and counseling. The Center's stated purpose is to enable handicapped children to reach their fullest potential while living at home. In addition to service-provision, they also train child health professionals from a wide variety of disciplines. They also conduct research on the prevention of developmental handicaps.

- Pediatric Health Care Demonstration Project: The Jackson Memorial Hospital received a three year grant from 8/01/88 to 7/31/91 for $759,000. The goal is to develop a model program to effectively address the special needs of HIV infected infants, children and women through the development of coordinated and comprehensive care and treatment at community-based facilities. The portion of the grant which goes to the Mailman Center is approximately $210,000. The Center focuses on psychological and psychosocial development of children with pediatric AIDS. They evaluate the psychological and psychosocial status of a child, and prescribe a regimen which will allow a child the greatest opportunity to be integrated into normal education programs. There is a home-based and center-based component. Most of the services are delivered at the child's home. Social workers typically visit the home 1-2 times a week; early childhood educators typically spend 3 hours a week with the children; physical therapists typically visit 1-2 times a week; a speech therapist visits 1-2 times a week if necessary. The center-based component is delivered at Debbie's School -- an early education center composed of an infant and toddler preschool, infant nursery, toddler nursery and preschool nursery, all of which are specifically for children with developmental disabilities. The project plans more cooperation with Dade County Public Schools and with Headstart in the future (Contact: Dr. John Seidel, Project Coordinator (305) 547-6624)

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August 18, 1989

Select Committee on Children,
  Youth and Families
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House Annex 2, Room 384
Washington, D. C. 20515

Abortion should not be encouraged or advocated for pregnant women who test positive for AIDS. The reasons are many and varied.

The social stigma attached to the diagnosis of AIDS is devastating and the concern of transmission to family, relatives and friends adds to the feelings of guilt and self worthlessness. Adding to all this, the trauma of a recommended abortion could be too much for an already devastated woman.

Careful monitoring of the fast moving medical literature on AIDS reveals that there is no uniformity on the recommendation of abortion as a solution for this catastrophic problem.

In reviewing the multiplicity of articles written on AIDS in the last few years, the common theme which can be deduced after studying them is that "Revised recommendations will be published as additional information is forthcoming."

In some studies three out of four infants born to HIV infected mothers were normal.

It is already admitted that the time period for counseling and monitoring seropositive patients can be prolonged into indeterminate number of years before the actual disease strikes. These patients during this time may well lead near normal lives, and during this indeterminate period, our understanding of the natural history of the infection will change and more effective therapies may be forthcoming.

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With the level of public concern so high and with misinformation so widespread, the greatest need now is for accurate information to be disseminated. The propagation of the notion that abortion is the best solution for the pregnant patient who is HIV positive should be discouraged. Even the recommendation of abortion for the pregnant patient seriously ill with AIDS can be questioned. Women so seriously ill may well die from the abortion operation as case histories in the obstetrics and gynecology literature have documented.

We all realize there is no quick fix solution to the ravages of AIDS. But to offer an abortion, the destruction of human life, to a woman whose life is already being destroyed, is offering her nothing but sadness. Let us pray for a more sanguine alternative.

Matthew J Bulfin M. D.

Matthew J. Bulfin, M. D.
President

MJB:ahr

New York Times pg. A18
8-8-89

# The Offensive Tactics of AIDS Ideologues

By Elizabeth M. Whelan

In June, I attended the Fifth International Conference on AIDS in Montreal. I came away with a deeply troubling fear that those in leadership positions in AIDS prevention programs — I'll call them the AIDS establishment — are totally out of touch with the reality of American culture and sensitivities. Unless their efforts are redirected, we may very well have more cases of AIDS, not less.

The meeting opened with the presentation of an AIDS manifesto demanding "full legal recognition of lesbian and gay relationships." While sidestepping the legitimacy of this issue, I think such recognition is not an essential part of an AIDS prevention program. It will serve only to alienate further those who are already squeamish about alternative sexual life styles.

People with AIDS waved wristwatches to signify that their time is running out, delaying the appearance of Prime Minister Brian Mulroney of Canada. They later attempted to drown out a speech by Dr. Stephen Joseph, New York City's Public Health Commissioner.

One plenary session speaker talked of the necessity of making condoms common items. He encouraged us to have our children play with condoms instead of balloons, stage condom blowing contests at birthday parties and work at ways of getting songs about condoms in the media.

He also explored the idea of having the Goodyear blimp replaced with a condom. While he was speaking, AIDS activists outside the conference hall inflated a seven-story yellow condom.

Another plenary speaker talked of the importance of teaching children about safer anal sex "without penetration" and later added that AIDS was good because it made the world "kinder." This same speaker stated that the Roman Catholic Church had to "yield on its opposition to condoms or watch the faithful die" — a naive, futile and uncreative approach to an institution guided by tradition.

> They're out of touch with America.

Yet another speaker summed up what I felt was the consensus of the AIDS establishment at this conference. He told us that, as a society, Americans had to choose between good health and "retrograde moralism" — whatever that is.

A representative of a prostitutes' group presented her music video, "Safe Sex Slut." As for the "AIDS art work" being displayed for "educational purposes" — featuring explicit homoeroticism — one person's attempts at AIDS education (possibly appropriate for homosexual men) is another person's pornography.

In my years of public health training, the curriculums always stressed the importance of "cultural sensitivity" in introducing health education into foreign cultures: Respect local mores or you will ultimately fail if your program runs up against social taboos.

Where is the sensitivity for those Americans who have closely held traditional values and beliefs about sexuality and its context? Are we not ultimately going to fail if we cannot work within the various subgroups of the heterogeneous society in which we live?

For example, is there not, while noting the usefulness of condoms in preventing AIDS transmission, room for discussing postponement of sexual intercourse until a monogamous relationship is established? I didn't hear a thing about that in Montreal.

Is there not room for taste and discretion in AIDS education? Concerns about morality and values aside, is there no tolerance in the AIDS establishment for those of us who believe, based on the medical evidence alone, that risk reduction is a much less desirable goal than risk elimination when it comes to advising people about how to avoid contracting a fatal disease?

There is no representation in the AIDS establishment that I can discern of the mainstream values and beliefs of most Americans. I am not talking here about those who argue mindlessly that sex education is not appropriate in schools. I am concerned about the open-minded person who realizes that AIDS is an extremely serious public health threat but does not want the beliefs of ideologues forced upon the majority.

If the aim of the AIDS establishment is truly to save lives and not merely to advance a political agenda, then AIDS education must be sophisticated and sensitive, and respect a diversity of values. □

*Elizabeth M. Whelan is president of the American Council on Science and Health, a consumer education group.*

HISPANIC AIDS AWARENESS PROGRAM
PROGRAMA DE INFORMACION SOBRE SIDA

MEMORANDUM

TO: Karabell Pizzagati

FROM: Fausto B. Gomez

DATE: August 7, 1989

SUBJECT: Testimony

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Thank you for affording us the opportunity to provide testimony to the Select Committee on Children, Youth, and Families concerning our research on AIDS and the South Florida Hispanic community. Our research data is significant in that it presents the only assessment of what South Florida Hispanics know and feel about AIDS. Since the knowledge and behavior of child-bearing age adults will, for the most part, determine the extent of the epidemic for the pediatric segment we think it important for the Committee to have this information.

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Sponsored by Educational Management Services, Inc. and the
State of Florida, Department of Health and Rehabilitative Services

HISPANIC AIDS AWARENESS PROGRAM
PROGRAMA DE INFORMACION SOBRE SIDA

TESTIMONY OF:

SANDRA VIGGIANI
PROGRAM OFFICER OF THE HISPANIC AIDS AWARENESS PROGRAM

AND

MANUEL MENDOZA
CONSULTANT TO THE HISPANIC AIDS AWARENESS PROGRAM

BEFORE THE:

SELECT COMMITTEE ON CHILDREN, YOUTH AND FAMILIES
UNITED STATES HOUSE OF REPRESENTATIVES

Miami, Florida August 7, 1989

1700 S.W. 57th Avenue, Suite 220 • Miami, Florida 33155 • (305) 262-2585
Sponsored by Educational Management Services, Inc. and the
State of Florida, Department of Health and Rehabilitative Services

Mr. Chairman and Honorable Members of the Committee:

In 1988 the Florida Legislature funded the Hispanic AIDS Awareness Program (HAAP) at Educational Management Services. The Legislature was concerned about the number of reported cases of Hispanics with AIDS and the limited resources available to conduct research, education, and information programs for the Spanish-speaking community of South Florida. The purpose of HAAP is to present facts, destroy myths, foster awareness, create support for constructive action, and influence the behavior of individuals.

As an important program initiative, HAAP has recently completed a comprehensive research effort aimed at assessing the general South Florida Hispanic population's knowledge, attitudes, beliefs, and behavior relating to AIDS. The program conducted four (4) focus group sessions with participants representative of the different nationalities comprising the Hispanic community of South Florida and a Knowledge, Attitude, and Behavior survey of 508 Hispanic residents. These activities are unique in South Florida and form the baseline for the continuing study of what Hispanics know and feel about AIDS. The results of the focus groups and survey reveal data that have important implications for pediatric cases, since the knowledge and behavior of child-bearing age adults will, for the most part, determine the extent of the epidemic for the pediatric segment.

The research conducted had a qualitative component through the series of focus groups and a quantitative component through the administration over the telephone of a specially derived questionnaire based on the beliefs and attitudes expressed by focus group participants and utilizing a core group of questions from the National Center for Health Statistics "AIDS Supplement."

A few of the most significant research findings are:

- Over 67% of those surveyed indicated that they were "somewhat or not very" informed about AIDS.

- Although 75.5% of the respondents believe there is something that they personally can do to avoid acquiring or transmitting the AIDS virus, only 31.9% considered themselves to have sufficient information to make effective changes in behavior.

- Only 32.3% of the respondents stated that fear of contracting the AIDS virus has caused them to change their sexual behavior. Young Cuban males are least likely to modify their behavior. This group indicated a heightened awareness, but only slight behavior modification. It appears that they are still taking risks, but worrying about it more. .

- Over 55% of the respondents were unaware of the difference between being infected with the HIV virus and having AIDS. A major risk is that infected individuals, who do not manifest symptoms, may not recognize the need to take precautions to avoid transmission and/or pregnancy.

- Almost 50% of the Hispanics sampled believe it possible to acquire AIDS by donating blood. This has caused a significant reduction in the local blood supply with negative ramifications for people of all ages, including children. Additionally, only 32.5% believe the blood supply is safe.

- Findings that bear specifically on children show that 44% of Hispanic parents have not discussed AIDS with their children and that 25% of the sample believe that children with AIDS should not be allowed to attend public schools (the percentage of women who believe the latter is significantly higher).

It is clear from the above findings that there is a need to increase AIDS informational and educational activities targeted to the Hispanic community. The research provides an objective base of information upon which decisions about message and communication channels can be made. Effective intervention strategies, derived from the focus groups and survey and verified through a field test, are being implemented by HAAP to increase levels of knowledge and education and affect behavior. (An outline of innovative educational strategies is available upon request, but has not been included since it falls outside the immediate scope of this hearing. Elements of the campaign include definition of objectives; identifying target audiences, message content, and communication channels; the use of research in program planning and evaluation; and, models of behavior change.)

In closing, allow us to thank this Committee for the opportunity to provide testimony and the Florida Legislature and the Department of Health and Rehabilitative Services for their sponsorship of the Hispanic AIDS Awareness Program. Their leadership and support have placed Florida at the forefront of the fight against AIDS.

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October 2, 1989

Margaret Oxtoby, M.D.
Epidemiologist in AIDS Surveillance
Centers of Disease Control
1600 Clifton Road, N.E.
Atlanta, GA 30333

Dear Dr. Oxtoby:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "AIDS and Young Children in South Florida," held on in Miami. Your testimony was, indeed, important to our work.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript to us by October 10, with any necessary corrections.

I would also appreciate it if you would answer the following for the record:

1. The Secretary's Work Group on Pediatric HIV infection made a number of recommendations. Has the Centers of Disease Control (CDC) developed a work plan and time frame to implement those recommendations? Is there a priority order for addressing the recommendations?

2. What results have been seen from he 8 perinatal AIDS prevention projects designed to promote more effective contraceptive use and family planning among HIV-infected and at-risk women?

3. Dr. Scott testified that over 7% of the seropositive women tested at Jackson are adolescents, underscoring the growing risk of HIV infection among teenagers and children that they may bear. You have noted in your testimony that adolescents be targeted as a unique group. However, it is my understanding that the CDC currently does not routinely report the full range of surveillance information on adolescents;

rather, they are grouped with adults for the major categories that reported.

Why doesn't CDC report on adolescents separately from adults? Are there plans to do so? If so, when? If not, why not?

Let me again express my thanks, and that of the other members of the Committee, for your participation.

Sincerely,

George Miller

GEORGE MILLER
Chairman
Select Committee on Children,
Youth, and Families

Enclosures

CC: Walter R. Dowdle, Ph.D.

## Response to Questions Posed by Congressman George Miller

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
Atlanta GA 30333

November 20, 1989

The Honorable George Miller
Chairman, Select Committee on
Children, Youth, and Families
United States House of Representatives
Washington, D.C. 20515

Dear Mr. Miller:

Thank you for your letter regarding the hearing in Miami entitled "AIDS and Young Children in South Florida." The reviewed transcript of Dr. Oxtoby's testimony is enclosed. Centers for Disease Control (CDC) has the following responses to the three questions raised in your letter.

1. CDC's response to the recommendations of the Secretary's Work Group

   The CDC participated in the Secretary's Work Group on Pediatric HIV Infection and supports the recommendations of that group, two of which directly concern CDC:

   Recommendation 3: "The CDC should convene a committee of expert consultants to discuss the need for expanding surveillance of HIV infection in children and adolescents and broadening the HIV classification system."

   Surveillance activities of HIV infection in children and adolescents currently undertaken at CDC include:

   - emphasizing ongoing national surveillance for AIDS cases and evaluating the completeness of case reporting;
   - conducting serosurveys of neonates in 40 States to help determine the extent of HIV infection among childbearing women;
   - expanding surveillance for all children with HIV infection in six geographic areas to evaluate the current AIDS case definition and classification system, to better describe the spectrum of HIV disease in children, and to explore the feasibility of expanding surveillance to include not just AIDS cases but all children diagnosed with HIV infection; and

- working with those States that now require reporting of HIV infection to develop a uniform reporting system.

A committee of expert consultants will be convened in 1990 to review these and other planned surveillance activities.

Recommendation 11: "Special education and prevention programs in settings other than schools must be developed for hard-to-reach adolescents, including minorities, drug abusers, runaways, and others."

Education and prevention programs for youth cannot be limited to school settings. CDC is providing fiscal and technical assistance to seven national organizations that address the special needs of these underserved adolescent populations through cooperative agreements. These organizations include: The National Organization of Black County Officials, the National Coalition of Hispanic Health and Human Services Organization, the National Coalition of Advocates for Students, the National Network of Runaway and Youth Services, the National Rural and Small Schools Consortium, the Association for the Advancement of Health Education; and the National Commission on Correctional Health Care.

2. Results from the Perinatal AIDS Prevention Projects

Eight perinatal AIDS prevention projects are underway to promote more effective contraceptive use and family planning among HIV-infected and at-risk women. Productive working relationships have been established between family planning providers and providers in settings serving women at high risk for HIV such as drug treatment clinics. Preliminary data on the results of these perinatal AIDS prevention projects is expected during calendar year 1990.

3. Separate Reporting of Adolescent AIDS Cases

AIDS cases are categorized according to sex and 5-year age groups in the monthly AIDS surveillance report. In addition to ongoing national surveillance of adolescent AIDS cases, HIV serosurveys are conducted in adolescent populations including hospital patients, and military and Job Corps applicants. All CDC-supported serosurveys collect information on age. Reports from these serosurveys will continue to include tables showing HIV prevalence rates in each age group.

I hope these answers are helpful to the Committee.

Sincerely yours,

Walter R. Dowdle, Ph.D.
Acting Director

Enclosure

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October 2, 1989

Gwendolynn Scott, M.D.
Department of Pediatrics, D4-4
University of Miami School of Medicine
P.O. Box 016960
Miami, FL 33101

Dear Dr. Scott:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "AIDS and Young Children in South Florida," held on in Miami. Your testimony was, indeed, important to our work.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript to us by October 10, with any necessary corrections.

I also would appreciate it if you would answer the following for the record:

1. Substance abuse is a significant factor in the increases in HIV infection. To what extent is substance abuse contributing to increases that you are seeing among pregnant women and young children at Jackson Memorial and in South Florida?

2. What efforts are there to work with clinics that provide WIC services, including referral of at-risk or HIV-infected women to WIC clinics so that they can get nutritional supplementation, formula for their infants, and referral to other services (e.g. prenatal care, drug abuse treatment)?

3. You noted that in a recent survey of pregnant women at Jackson Memorial, 2.1% of those tested were HIV-antibody positive and 7.3% were adolescents. Are there special research or prevention activities underway or planned that target adolescent populations who are at high risk?

4. You make eight recommendations. Among them, are there priority areas which should be addressed first?

Let me again express my thanks, and that of the other members of the Committee, for your participation.

Sincerely,

George Miller

GEORGE MILLER
Chairman
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TELEPHONE 226-7692

October 2, 1989

Deana James, M.D.
Medical and Executive Director
C.L. Brumback Community Health Center
38754 State Road 80
Belle Glade, FL  33430

Dear Dr. James:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "AIDS and Young Children in South Florida," held on in Miami. Your testimony was, indeed, important to our work.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript to us by October 10, with any necessary corrections.

I also would appreciate it if you would answer the following for the record:

> What do you think needs to be done in West Palm Beach in terms of services, resources and other mechanisms to address the increasing problems of HIV infection generally, and particularly among regnant women and young children?

Let me again express my thanks, and that of the other members of the Committee, for your participation.

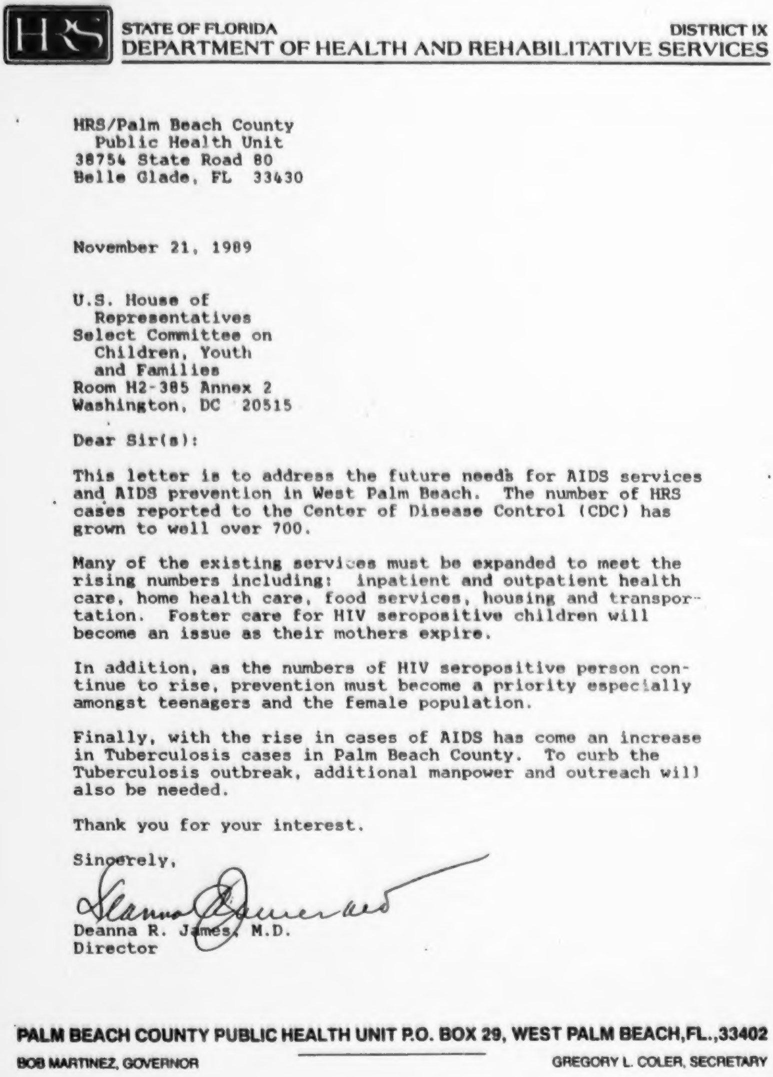
Sincerely,

George Miller

GEORGE MILLER
Chairman
Select Committee on Children,
Youth, and Families

Enclosures

## LETTER TO SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES WITH RESPONSE TO QUESTION POSED BY CONGRESSMAN GEORGE MILLER



HRS STATE OF FLORIDA DISTRICT IX
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

HRS/Palm Beach County
Public Health Unit
38754 State Road 80
Belle Glade, FL 33430

November 21, 1989

U.S. House of
Representatives
Select Committee on
Children, Youth
and Families
Room H2-385 Annex 2
Washington, DC 20515

Dear Sir(s):

This letter is to address the future needs for AIDS services and AIDS prevention in West Palm Beach. The number of HRS cases reported to the Center of Disease Control (CDC) has grown to well over 700.

Many of the existing services must be expanded to meet the rising numbers including: inpatient and outpatient health care, home health care, food services, housing and transportation. Foster care for HIV seropositive children will become an issue as their mothers expire.

In addition, as the numbers of HIV seropositive person continue to rise, prevention must become a priority especially amongst teenagers and the female population.

Finally, with the rise in cases of AIDS has come an increase in Tuberculosis cases in Palm Beach County. To curb the Tuberculosis outbreak, additional manpower and outreach will also be needed.

Thank you for your interest.

Sincerely,

Deanna R. James, M.D.
Director

PALM BEACH COUNTY PUBLIC HEALTH UNIT P.O. BOX 29, WEST PALM BEACH,FL.,33402
BOB MARTINEZ, GOVERNOR
GREGORY L. COLER, SECRETARY

[illegible]

U.S. House of Representatives
SELECT COMMITTEE ON
CHILDREN, YOUTH, AND FAMILIES
385 House Office Building Annex 2
Washington, DC 20515

[illegible]

October 2, 1989

Ms. Ana Garcia, M.S.W.
University of Miami
Department of Obstetrics and Gynecology
P.O. Box 016960
Miami, FL 33101

Dear Ms. Garcia:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "AIDS and Young Children in South Florida," held on in Miami. Your testimony was, indeed, important to our work.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript to us by October 10, with any necessary corrections.

I also would appreciate it if you would answer the following for the record:

1. Would you elaborate on the barriers to placement of HIV-infected children with nuclear or extended family members?
2. I understand that the state has developed a special foster care maintenance rate for an HIV-infected child who is placed in foster care. What is it? Is it adequate? How well does the process work?
3. What specific medical and social services are covered by the Medicaid waivers that the state uses for HIV-infected children?
4. Have you encountered problems in mainstreaming HIV-infected children in he public schools or Head Start programs?

Let me again express my thanks, and that of the other members of the Committee, for your participation.

Sincerely,

George Miller

GEORGE MILLER
Chairman
Select Committee on Children,
Youth, and Families

Enclosures